

The anticipated expansion includes:

- 5% pay increase in FY 2001 at a cost of 37,440
- To expand the blind production workforce by 3 additional production employees - \$42,840.00
- To provide a sufficient inventory of raw materials and to modernize production equipment, \$167,479. Of this amount, \$48,200 will be used to modernize production equipment and \$119,279 will be used to maintain a sufficient inventory of raw materials.

### **III. MASSACHUSETTS REHABILITATION COMMISSION**

# **MASSACHUSETTS REHABILITATION COMMISSION**

## **BACKGROUND AND MISSION**

The Massachusetts Rehabilitation Commission was established in 1955 for the purpose of assisting persons with disabilities to secure gainful employment. The mission of the agency has been greatly expanded throughout the years. The Disability Determination Services Division was established in the early 1960's and the MRC Independent Living Services Division was developed in the 1980's.

Today, the purpose of the Massachusetts Rehabilitation Commission is to provide comprehensive services with and for people with disabilities that will maximize their quality of life and economic self-sufficiency in the community. This is accomplished through multiple programs in the three divisions of MRC: the Vocational Rehabilitation Services Division, the Independent Living Division and the Disability Determination Services Division.

Approximately 12% of the population have a disability; there are approximately 736,000 individuals with disabilities living in Massachusetts. The Massachusetts Rehabilitation Commission serves consumers with a range of disabilities and chronic diseases, including but not limited to orthopedic disabilities, psychiatric disabilities, substance abuse, learning disabilities, mental retardation, sensory disabilities and neurological disabilities, including paralysis caused by brain and spinal cord injury.

## **VOCATIONAL REHABILITATION DIVISION**

- 1. 4120-1000 Administrative Services**  
**FY'98 Funding: \$304,501**  
**FY'99 Funding: \$362,662**  
**Current FY'2000 Funding: \$366,692**  
**FY'01 Proposed Funding: \$604,501**  
**Total 1 Year Increase from FY'2000: \$237,809**  
**Total Expansion from FY'98 – FY'01: \$485,513**

### **Increase from FY '98**

### **Total Expansion from FY '98**

FY 1999 \$ 58,161  
FY 2000 \$ 4,030  
FY 2001 \$300,000

\$ 58,161  
\$ 62,191  
\$362,191

The Massachusetts Rehabilitation Commission recommends that these amounts be allocated for the continued purpose of complying with the regulations in Title I of The Rehabilitation Act which prohibit Title I funds from being used to cover costs related to non-Title I federal programs. This would include positions for MRC Contracting, Legal and Personnel services provided to the MRC-IL Division.

The amount specified would be utilized to offset federal administrative expenses for the agency's fully-funded state staff and services. These positions are currently federally funded although the majority of responsibilities are for administration of state programs.

- 2. 4120-2000 Public Vocational Rehabilitation Services**  
**FY'98 Funding: \$6,322,114**  
**FY'99 Funding: \$6,405,313**  
**Current FY'2000 Funding: \$7,408,666**  
**Total 1 Year Increase from FY'2000: \$996,647**  
**FY'01 Proposed Funding: \$8,405,313**  
**Total Expansion from FY'98 – FY'01: \$4,505,900**

<u>Increase from FY '98</u>	<u>Total Expansion from FY '98</u>
FY 1999 \$ 83,199	\$ 83,199
FY 2000 \$1,086,552	\$1,169,751
FY 2001 \$2,083,199	\$3,252,950

The MRC administers the Public Vocational Rehabilitation Program which assists people with disabilities to go to work. Presently, MRC serves over 36,000 people with disabilities annually, has 22,800 people in active vocational service plans, and will place over 4,600 people with disabilities in competitive jobs commensurate with their abilities this year.

Federal appropriations in FY'99 resulted in only a 2.4% increase in federal VR funds for Massachusetts. In federal FY 2000 we do not expect an increase, even as large as that of FY'99. These minute increases have not kept pace with the effects of collective bargaining increases the increased cost of services purchased for our consumers to go to work, and the double digit increase in demand for our services by consumers with significant disabilities.

The MRC has instituted a waiting list for consumers who need purchased services to go to work. This action is made necessary because of an increase of 2-3,000 people with disabilities in MRC's, and due to a lack of increased federal funding in recent years sufficient to keep pace with inflation and the increased customer demand.

The State Year 2000 budget recognizes these facts and appropriated an additional \$1 million in funds to assist in relieving some from the waiting list for services paid by the MRC Vocational Rehabilitation Program. In addition, the Board of Higher Education voted to waive state college tuitions for MRC Vocational Rehabilitation clients to attend community and state colleges operated by the Commonwealth. It is estimated that an additional \$1 million would keep the waiting list to be less than 1,000 consumers for a period of about two months.

The VR Program entered into an Order of Client Service Selection, which limits direct services to individuals deemed "significantly disabled", in 1997. Insufficient funding made it impossible for the agency to assure that VR services would be available to all individuals in the Commonwealth eligible for services. The federal dollar allotment to the MRC Vocational Rehabilitation Program for federal year 2000 and beyond will not be sufficient to allow the MRC to abolish the present Order of Client Service Selection. The lack of increased federal funding will result in a continued waiting list for Vocational Rehabilitation services paid by the MRC vocational program for the foreseeable future. A waiting list will affect all individuals with disabilities including those with the most significant disabilities. A waiting list will have a direct impact on the ability of individuals with disabilities in the Commonwealth to obtain work.

### **Special Services**

The VR Services Program, which includes the Statewide Employment Services Department, has unique services for MRC Consumers. The VR Services Program provides assistance and information regarding SSI Work Incentives. The Social Security Administration, in cooperation with a MRC VRS counselor, can assist a consumer with phasing-out from the SSI and SSDI Programs. Over 300 people received this type of information in 1999.

The Van Modification Program, designed to assist eligible VRS consumers who are ready for employment, provides funds to adapt a van for their use. More than 50 VRS consumers benefited from this program in 1999. The Adaptive Housing Program contracts with an approved architect to design and arrange construction and/or modifications to the entrance and bathroom at the home of an eligible VRS consumer. More than 100 consumers were served in 1999.

Of course there are numerous VR Services provided on a continual basis. The VR Services Program provides Post Employment Services to a consumer who graduates from the Program and needs additional services to stay in the working world. Consumers who are non-English speaking can be served by VRS counselors able to speak their language or arrange for an interpreter.

Special services also focus on such unique populations as persons allergic to perfumes, cosmetics worn by others.

**CONSUMERS SERVED-FACTS AT A GLANCE** *(as of 1999)*

Consumers with open cases in the system	37,180
Consumers in active participation	22,862
Consumers still employed after one year	71%
Consumers satisfied overall with agency services	80%
Consumers who would recommend a friend to the agency	84%

**RETURN ON INVESTMENT BY CREATING TAXPAYERS**

- 4,756 citizens with disabilities were placed in employment last year.
- The earnings of these rehabilitated employees in MA have been increased by \$44 million.
- Federal and state taxes paid by these MA employees were estimated at \$4.4 million.
- Savings from the SSI and DI Trust Funds from people rehabilitated in MA in FY'99 were \$17.5 million.
- For every VR dollar spent on services in MA, a consumer earns an \$11.30 increase in taxable earnings.





**Our Consumers are Individuals with:**

Psychological Disabilities	30%
Substance Abuse and Related Disabilities	21%
Orthopedic Disabilities	16%
Learning Disabilities	7%
Mental Retardation	6%
Deaf and Hard of Hearing	6%
Neurological Disabilities	3%
Traumatic Brain Injury	6%
Other Disabilities	5%

## **What MRC Clients Have To Say about Vocational Rehabilitation Services**

### **From a Western Mass. MRC Consumer**

“I have been eligible for Rehabilitation Commission Services due to my mental disability. I wish to tell you of my favorable experience with the Pittsfield and Greenfield offices and thank you for the financial support I received this school year while I attended Greenfield Community College. I am truly grateful for the generosity your office has shown to me. It was money well spent; according to the Outdoor Leadership Program’s Coordinator I excelled in many areas to become one of the strongest students in my class. I would never have been able to attend school if it were not for your help. My new skills as an outdoor leader now complement my previous experience as a social worker for troubled youth and I am excited to begin this new part of my life.”

### **From a Northeast District MRC Consumer**

“This letter is only a small expression of my gratitude to you and all the others at Mass. Rehab. Thank God for the safety net that is in place nationwide that provides vocational services and counseling.”

### **From a Nonprofit Provider – Partner with the MRC**

“I have received MRC services in my life and I am grateful for the assistance that I have received. Human service work brings people back to productivity. I came back. These services worked for me.

If we want to create opportunities for other people like myself, we have to pay a good wage and stop the high turnover in human service work.

Let us show our respect for these workers by paying them a good wage.”

### **From an Employer on Cape Cod**

“Richard was born in Brockton, Massachusetts in 1953 and currently resides in Boston’s North End. In 1980 Richard graduated from Boston College with a B.A. in Studio Arts. He began attending Gateway Crafts in July, 1998.

Richard’s interest in sculpture was inspired by his earliest memories of the brilliance of Christmas ornaments and lights, his interest in watercolor from a delight with the variety of color in autumn leaves. To this day Richard’s favorite watercolorists are Charles Demuth and John Singer Sargent.

Richard’s work has been shown at the Fuller Art Museum in Brockton in 1974, at the Exhibition Hall of Boston College in 1980. His work was also included in *Shadows and Light: Recovered*

*Dreams and The Presence of Art and Art as Presents* at the Gateway Gallery in 1999 & 1998 respectively. Richard has been a client of MRC since 1990.”

- 3. 4120-3000 Employment Services**  
**FY'98 Funding: \$6,822,092**  
**FY'99 Funding: \$7,656,896**  
**Current FY'2000 Funding: \$8,330,747 \***  
**FY'01 Proposed Funding: \$12,986,566**  
**Total 1 Year Increase from FY'2000: \$4,655,819**  
**Total Expansion from FY'98 – FY'01: \$9,018,456**

*\* includes \$145,944 in provider salary increases*

### **Program Description:**

This account provides employment supports to individuals in segregated and integrated settings in the community. The program models developed under this account include extended employment, and supported work/employment. The supports provided through these programs allow individuals to either move into integrated employment opportunities or obtain and maintain competitive employment while decreasing their dependence on public assistance.

<b>Increase from FY'98</b>	<b>Total Expansion from FY'98</b>
FY'1999 \$ 834,804	\$ 834,804
FY'2000 \$1,508,655*	\$2,343,459
FY'2001 \$6,164,474	\$9,018,456

*\* (includes \$145,944 in providers salary reserve)*

### **Reason for Expansion:**

The Massachusetts Rehabilitation Commission (MRC) and state employment providers have been providing services to individuals with severe disabilities so that they can maintain their employment status and obtain more and better paying jobs in the community. The budget for these services has been minimally increased over the last few years. Consequently, in partnership with its providers; MRC has been unable to continue with providing this services to individuals.

At the same time the MRC has been unable to adjust provider rates to reflect real costs. The impact continues to be that fewer people with disabilities are coming off of public assistance and an increase waiting list for services is being created. It has been necessary to reduce the workforce from 1607 in FY'95 to 1280 in FY'98. The need to reduce this workforce has perpetuated the chronic unemployment problem among people with severe disabilities.

### **Justification for Expansion:**

FY' 2001    Enable the MRC to recognize the real costs for services and administration necessary to offer supports services and service coordination to approximately 460 individuals with severe disabilities including those on the waiting list and any new referrals. The real cost of these services using current expenses for services and administration would be \$4,655,819

The MRC Employment Services Program is expected to be eligible, at least in part, for Federal Financial Participation (FFP) from Medicaid during the FY'2000 budget period. MRC is developing a plan with DMR to participate in the DMR Community Based Waiver to cover the DMR eligible people served in this program under the waiver.

## **INDEPENDENT LIVING DIVISION**

- 1. 4120-4000 Independent Living Centers**  
**Funding FY'98: \$1,614,851**  
**Funding FY'99: \$2,514,851**  
**Current FY'2000 Funding: \$3,321,851\***  
**FY'01 Proposed Funding: \$4,721,851**  
**Total 1 Year Increase from FY'2000: \$1,400,000**  
**\*includes \$24,000 in provider salary increases**

### **Program Description:**

The Independent Living Centers Program provides funding for 10 Independent Living Centers (*ILC's*) across the state of Massachusetts. The 10 ILC's provide consumer controlled and consumer delivered independent living skills training, peer counseling, information and referral, individual advocacy and a range of other services to individuals with severe disabilities to enable them to live in the community. In addition, the ILC's provide community education and systems advocacy on behalf of all people with disabilities for the communities to become accessible to all its citizens. An increase in each year of:

<b><u>Increase from FY '98</u></b>	<b><u>Total Expansion from FY '98</u></b>
FY '99 \$ 900,000	\$ 900,000
FY '00 \$ 783,000	\$1,683,000
FY '01 \$ 1,400,000	\$3,083,000

### **Reason for Expansion**

The Independent Living Centers Program began in 1974 with federal innovation and expansion funding and continues with a federal formula grant based on population and size. The state began appropriating funds to supplement the federal funding in 1984. The combination of state and federal funding allowed 6 ILC's to offer services, on a regional basis only, with offices in the largest city in each of the regions. Consumer input in the mid-eighties convinced MRC and the Legislature to add 2 new ILC's and 2 satellites of existing ILC's in 1986, as well as another new ILC in 1990.

From FY'90 to FY'98, the IL Centers Program had seen no significant increases in funding and had faced several cutbacks. In FY'98, the program was awarded an additional \$210,000 and in FY'99 an increase of \$900,000 to expand services to approximately 550 individuals.

In FFY '99, the ILC's provided direct services from all sources of funding to 5203 individuals with severe disabilities across the Commonwealth.

Massachusetts 1990 Census data\* identifies 605,723 people with disabilities, aged 16 and over, comprising 12.85% of the Commonwealth's population. In addition, 12.24% or 736,183 of the population are members of racial minorities. It is unknown what percentage of persons who are racial minorities are disabled, but it is believed to be quite high due to economic factors that influence the onset of a disability.

It would be difficult for MRC to state that every person with a "work", "self-care" or "mobility" disability as reported in the 1990 census was in need of independent living services. But if we estimated that just 10% (60,572) needed and wanted services, we could easily see the need for expansion of funding is quite dramatic. To illustrate this point, the following examples are presented:

Example 1: The city of Taunton has a population of 49,832 of which 5,298 (10.6%) have identified themselves, for the purpose of the census, as having a disability. The ILC serving this town reported in FFY '96 as having provided direct services to 38 individuals with disabilities.

Example 2: Springfield, the 2<sup>nd</sup> largest city in the Commonwealth, has a population of 156,983 of which 57,114 (36%) are racial minorities and 19,665 (12.5%) are individuals with disabilities over age 16. In FFY '96, the ILC serving Springfield provided direct services to 749 individuals with disabilities. This is only 3% of those identified by the 1990 census as having a disability. Given the large minority population in the Greater Springfield area, outreach and services are necessary to address the unserved needs of racial minorities with disabilities living in this area.

Example 3: The 45 cities and towns in the Metropolitan Boston area have a population of 1.9 million of which 371,446 (19%) are racial minorities and 199,297 (12.54%) are individuals with disabilities aged 16 and over. The ILC serving the Greater Boston area provided direct services to 966 (< .01%) individuals with disabilities during FFY '96 of which only 160 (< .01%) were racial minorities.

It is clear from these examples the ILC's need expansion funding in order to address the unmet IL needs of people with disabilities, particularly those with minority backgrounds. People with disabilities living in the cities and towns farthest from an ILC office face the greatest need due to lack of an accessible, affordable transportation system available to people with disabilities in other parts of the state.

As a whole, minorities with disabilities remain underserved for a number of reasons, including, but not limited to a lack of available role models. ILC's need to develop plans to educate members of minority communities regarding IL services. These plans would call for additional funds to provide desperately needed minority peer role models.

The ILC's are just scratching the surface of those needing and wanting services to enable them to leave institutions, nursing homes and dependent home situations. These individuals want to live productive



lives in the community, have families, get jobs, pay taxes and participate in the wide range of social roles available to others in their community.

The FY '00 expansion request encompassed the following:

- The need for \$900,000 for the 10 ILC's to conduct outreach and provide independent living services to 550 people with disabilities presently unserved and/or on a waiting list for services, including those from racial minority groups. Most ILC's do not have formal "waiting lists". They try to give a little service to everyone, which sometimes compromises quality and only addresses the immediate or "crisis" needs of the consumer. This approach has also resulted in high staff turnover in some ILC's due to burnout, as demand exceeds available resources.

In addition to the need for "core" independent living services to be expanded to underserved groups, the lack of services for individuals with disabilities who are parents was identified at the public hearings. Raised at the Southeast Regional hearings, this need is probably statewide and includes the following: advocacy and sensitivity training at D.S.S. for parents with disabilities who need supports for their family, expanded homecare services for children of individuals with disabilities, case management to assist parents with disabilities to navigate state agency services, and other similar services.

Information provided after the hearing included vignettes of 15 parents with disabilities struggling to keep their families together. One of the stories included a single mother with a mobility impairment and attention deficit disorder. She has two children, one teenager with quadriplegia and an elementary school-aged child. Mom is attending school to increase her future employment options. She needs reliable transportation, respite care from family pressures and help finding a personal care service provider for her older child. This mother would greatly benefit from receiving assistance with daily chores and care of her children when at school. It is critically important to understand that she is reluctant to ask for assistance from D.S.S. or other state agencies. Her greatest fear is that she will be discriminated against on the basis of her disabilities and will lose custody of her children.

MRC wishes to acknowledge these needs in this document although staff have not had the opportunity to gather more in-depth information and examine how best to meet these needs at this time. Any initiative undertaken to address the above issues will require additional funding in future years.

### **FY'00 BUDGET EXPANSION**

MRC requested an expansion of \$1,600,000 in FY'01 to provide for those items not funded in FY'99 (\$400,000) and an expansion of an additional \$1,200,000.

Those items not funded in FY'99 included funds for the ongoing training of ILC staff and boards; ongoing support and training of the IL Access management information system implemented in FY'99; funds for computer and assistive technology for IL Center staff; consumer involvement funds for the State Independent Living Council and 100 individuals awaiting services.

With the additional \$1,200,000, the ILC's would provide direct services to an additional 600 individuals and these funds will be specifically targeted towards meeting the needs of individuals from minority communities, who may respond more appropriately to bilingual, bicultural staff, and other unserved groups through the expansion of existing programs or establishment of new Centers or satellites.

The State Independent Living Council analyzed census and ILC data of individuals served to identify areas in the state most in need of funds to establish or maintain satellites or branch offices or to create new ILC's. The SILC, at its November 1998 meeting, presented some preliminary findings and a priority was adopted to look at the needs of individuals with disabilities living in the Greater Boston area. At the MRC/MCB/MCDHH public forums several individuals presented testimony on the IL needs of individuals with disabilities who are minorities residing in the Boston area..

MRC proposed of the \$1,200,000 expansion that \$500,000 is set aside for new ILC's or satellites of an existing ILC in the Boston area to address the needs of underserved individuals living in the Greater Boston area including the inner city neighborhoods. The SILC also supported, as did MACRO, a COLA of 3-4% for providers to address the rising costs for doing business. This COLA would be \$95,000 for the ILC's in addition to approximately \$35,000 in salary upgrade funds. The remaining \$570,000 would be distributed utilizing the State Plan approved allocation formula. Funds to each ILC would be utilized to meet the IL needs of those on waiting lists and underserved populations, including those from minority communities statewide. As identified in previous narrative, each ILC has racial and ethnic minorities who could benefit from staff of the same race or ethnic background to provide true "peer" support and services. It was anticipated an additional 600 individuals with disabilities will receive services with FY'00 expansion funding.

The FY'00 budget, when signed in November, provided a \$783,000 increase in funding. An RFR will be released in the late winter to establish a new IL Center or satellite of an existing ILC in the Greater Boston area. The start up of this Center is expected to occur in April 2000. Funds were allocated to each ILC based on a formula approved in the State Plan for Independent Living. This increase also included a 3% COLA. Increased funds will improve the Centers capacity to reach underserved individuals and those on waiting lists. In addition funds were set aside to provide training for ILC boards and staff, consumer involvement expenses of the State Independent Living Council, technology needs of ILC staff, and development of a state funded position at MRC. Because the budget was passed so late, the IL budget was prorated and approximately \$400,000 was identified to provide one time assistive technology services to individuals with severe physical disabilities (see Assistive Technology section). These funds will be needed to annualize ILC and MRC costs in FY'01.

### **FY'01 EXPANSION**

The FY '01 expansion request of \$1,400,000 is to provide expansion in the following areas; the creation of 2 new ILC locations, either as a satellite of an existing center or as a free standing ILC; expansion of services in the existing network of ILC to underserved disability groups or geographic areas and to continue to build the infrastructure of the program within MRC including the development of a skills training curricula and training module for ILC staff and consumers.

New locations are necessary to make the IL services even more locally based than they are now. MRC had hoped to open 2 new ILC offices in FY'00 but due to funding was only able to provide for one. The lack of affordable, accessible transportation throughout the state severely limits the travel capacity of many individuals with disabilities, particularly those with mobility impairments. ILC staff does travel to the homes of individual consumers, but doing so reduces the number of people to whom they can provide services in a given day. In addition to the provision of direct consumer services, the ILC's also provide community education and systems advocacy to assist local communities in becoming more accessible to their citizens. ILC's have found that many cities and towns do not want to work with them because the ILC is not considered part of their "community", especially if the office is located many towns away.

The Governor-appointed State Independent Living Council is in the process of developing the expansion needs for ILC's in the Commonwealth. The organization is evaluating where new Center sites should be located when funds become available. Preliminary data shows a great need in the Greater Boston area and in the South Shore. Based on past experience, MRC recommends initial funding of \$275,000 to \$300,000 per site with a minimum population base of 200,000-300,000 people. Each location will serve an additional 175 individuals, as well as the community in general.

The existing network of ILCenters continue to need expansion funds to deal with the great need for IL services in the community. The ILC's could play a role in outreaching to individuals with severe disabilities in nursing homes and working in partnership with state agencies to develop plans for individuals desiring to live in the community to prepare them for community living. Centers have a great need to identify and hire qualified, bi-cultural and bi-lingual staff to conduct outreach and provide services to multicultural communities. Centers have had difficulty attracting qualified individuals with disabilities to work on staff. A review of staff salaries needs to occur to ensure they can attract staff to provide quality services. Salary upgrades and reasonable administrative costs must be considered.

Without recommended funding the ILC program will continue to serve a very small number of people with severe disabilities, representing only a fraction of those in need. For those individuals not being served, it will mean continuing to live in institutions or inappropriate settings such as shelters and hospitals, or even in worse, abusive home settings. As stated previously, it means not being able, to participate in society, go to the market, practice their religion or exercise the right to vote. It means the Commonwealth will continue to spending millions in Medicaid funds for individuals whom, with IL supports in the community, may otherwise work and buy Medicaid through the CommonHealth Program.

### **Medicaid/FFP**

It is believed that at least some of the services offered by the ILC's will be Medicaid FFP.

## **Improved Program Outcomes**

A better outcome for this program would be to provide more individuals with quality services in a more timely fashion. Additional resources and services will improve the quality of life of thousands of people with disabilities who want to take their rightful place in society. This promotes community integration and encourages individuals with disabilities to get involved in the community through volunteerism or paid employment. It also means increasing the percent of services delivered to people from racial/ethnic minority groups.

Having the supports to provide better outcomes, such as appropriate technology, staff training, consumer involvement and contract information to assess performance against goals is also necessary. The addition of a contract monitor will ensure continued improvement in the capacity and efficiency of the providers in order to maximize the effectiveness of service dollars.

## **ILC Consumer Profile #1**

Mrs. N, on a vacation in Bermuda with her husband, had an accident with her motor bike and sustained in a severe spinal cord injury. She became quadriplegic and unable to breathe on her own without the assistance of a ventilator. While hospitalized in a Boston area rehabilitation center, a MRC representative met with her, her husband and daughters to talk about her plans post-discharge. Mrs. N and family would only consider the option for her to return to their home on the North Shore. With those plans, the MRC counselor referred Mrs. N and her family to the local Independent Living Center to begin to work with the ILC and hospital staff on all the supports that would need to be in place pre- and post-discharge.

Besides the enormously expensive equipment she required, such as a sip-and-puff wheelchair, ventilator, hospital bed, medical supplies, and more (*primarily covered by her insurance*), there was also a need for home modifications to enable her to get in and out of her house. Additionally, Mrs. N would now need staff to assist her on a daily basis with her personal care.

Mrs. N's insurance would not cover personal care assistants (*PCA's*) so it was essential she become Medicaid eligible to pay for PCA's to allow her to go home. Because her husband's income created a huge "spend-down" which they really couldn't afford to spend to become Medicaid eligible, it appeared the plan to return home would not be feasible. However, the ILC staff knew of a little utilized federal regulation called the "spousal deeming waiver" which allowed Medicaid to only look at her income. As a result, she became Medicaid eligible and the ILC staff assisted her in getting approval for 24 hour PCA coverage. MRC provided the funds for a ramp.

Since her discharge from the rehabilitation hospital in 1981, Mrs. N has lived at home with her husband with the assistance of PCA's. The ILC staff have worked with her on many issues over the years, especially advocating for continued Medicaid eligibility in the face of changing regulations and priorities.

Mrs. N died last year at the age of 80. The last 15 years were not what she had envisioned for her “golden” years. However, with the support of her family, ILC staff and PCA’s she was able to maintain a quality to her life that would otherwise have been lived out in a nursing home because of the severity of her disability.

The Commonwealth spent between \$60,000 - \$76,000 per year on PCA’s to keep her at home. This is a substantial amount of money, but still a fraction of the cost of institutional care. One can not easily measure the cost of the quality of life, particularly when it was lived in the way in which she choose to live it.

## **ILC Consumer Profile #2**

A 49-year old male with psychological disabilities in Milford was seeking volunteer positions. He was not able to find any volunteer positions because he was not able to work in an office setting. CLW, Inc. met with the man and developed a volunteer advocacy position to accommodate his disabilities. He is currently helping maintain a PCA pool list and has become a strong advocate for the IL Philosophy. He is now considering working as a peer counselor at CLW, Inc. his local ILC.

### **2. 4120-4000 Turning 22 Services**

**FY’98 Funding: \$993,338**

**FY’99 Funding: \$1,193,338**

**Current FY’2000 Funding: \$1,690,833\***

**FY01 Proposed Funding: \$3,608,782**

**Total 1 Year Increase from FY’2000: \$1,917,949**

\*Includes salary reserve of \$11,707

The MRC Turning 22 Independent Living Program serves the needs of young adults with severe physical disabilities transitioning from special education to adult human services as well as individuals with traumatic brain injuries served through our Statewide Head Injury Program. The IL Turning 22 Program provides two components: 1) Supported Living Program; and 2) “Transition to Adulthood Program”, which provides independent living skills training in the school system through early intervention services. MRC is seeking the following increase for the next three years:

<b><u>Increase from FY ‘98</u></b>	<b><u>Total Expansion from FY ‘98 – FY’01</u></b>
FY ‘99 \$ 200,000	\$ 200,000
FY ‘00 \$ 485,788	\$ 685,788
FY ‘01 \$1,917,949	\$2,603,737

A new account for Turning 22 Services (T22) should be established, similar to DMR, for newly appropriated funds for MRC provided services to T22 consumers, whether they be services delivered by Vocational Rehabilitation (VR), Independent Living (IL) or the Statewide Head Injury Programs (SHIP). For the following year, funds will be annualized into the base of the appropriate account.

The T22 IL Program received \$200,000 from the legislature in FY99. Funds were spent for case coordination to 6 new consumers; adaptive housing and other necessary ancillary services for existing consumers. SHIP initiated funding for five Turning 22 consumers for residential services, staffed apartments, supported living, and family supports.

**Supported Living Program:** Provides case coordination services for consumers who are living in the community. Case coordinators assist consumers with such services as organizing their households, helping consumers hire/fire PCA's, helping them with budgeting and finances, or any other needs identified by the consumer. Without case coordination supports, these individuals would not be able to live in the community and would require some form of institutionalization. Most of the consumers in this program are able to leave institutional settings as a result of these minimal program supports. The Supported Living (SL) model incorporates the independent living model of consumer control and choice, encouraging consumers to empower themselves by active participation in decisions, which affect their lives. MRC-IL has contracts with seven SL Providers throughout the state, and consumers have a choice in the Provider they wish to work with.

There is also a long-identified need for persons with learning disabilities/cognitive impairments to receive supported living services. These are individuals with a variety of severe learning and emotional disabilities who need relatively minimal ongoing residential support services but who do not fall under the jurisdiction of DMR or DMH. A proposed pilot project would allow for outreach, assessment, and services to a relatively small group of such individuals. Most recently, a need has been identified at the Coting School in Lexington where there has been a shift from students with severe physical disabilities to a larger number who have severe learning disabilities. Additional funding in FY01 would provide for a pilot program for 10 new consumers who have severe learning disabilities and do not meet DMR/DMH eligibility @\$4,000 /consumer /year =\$40,000.

**Transition to Adulthood Program:** Provides skills trainers (*who themselves have a disability*) from two IL centers to provide skills training, social skills building, advocacy, and peer counseling in their school setting. The majority of TAP consumers are served through Massachusetts Hospital School in Canton, but many consumers also receive skills training through public school systems in the Boston and Northeast areas, while some are served through the Coting School in Lexington. It has been found that early intervention assists consumers to live more successfully on their own in the community, helps them make more informative decisions about issues affecting their daily lives, and also decreases the cost of ongoing post-graduation services. MRC-IL has contracts with two ILC's in the Boston and Northeast areas.

**Turning 22 SHIP Consumers:** These consumers have traumatic brain injuries and are in need of residential services, 24 hour staffed apartments, supported living/case management, family supports, evaluations, and adaptive equipment to help them become more independent or live in the least restrictive environment.

### **Expansion For TAP:**

The number of TAP referrals will rise from an estimated 160 in FY'00 to an estimated 300 by FY'01 because we will be asking for additional monies for independent living centers which currently do not have Turning 22 funding. Additional funding in FY01 will allow for four positions in other ILC's throughout the state to provide outreach to students with severe physical disabilities who are attending public school systems. Skills trainers will do outreach in the schools to work with students on issues of independent living and self-advocacy. They will also work with MRC to coordinate ITPs, as well as preparing students for the possibility of using supported living case coordination once they move out



on their own. Without expansion of TAP, a large number of special education students in the central, western, and southeastern regions of the state will have limited access to independent living skills training, and, therefore, are at risk of institutionalization or living in unproductive dependent family situations.

The Department of Education reports that for 1996-97 public school enrollment was 935,623 students of which 55,128 or 16.6% were students receiving special education services. The Department of Education also reports that special education students in “regular” classrooms are on the rise over the last 7 years from 10.2% to 15.9%. This means that fewer students are placed in out of district programs and in separate programs. The students in these programs need access and opportunities to participate in activities and services with and without other students with disabilities.

The Independent Living Center for the North Shore reports that of the 14 public school districts in the North Shore region there are 3,130 SPED students in grades 8-12. Because of the lack of funding to target students with disabilities they were only able to provide services to 13 individuals ages 14-22.

The Stavros Center for Independent Living, which covers Hampton, Hampshire, and Franklin counties, report a list of 18 students with disabilities that are approaching 22 and have transition issues. Most of the requests for services are around the need for advocacy to receive services under special education such as placement in mainstream programs, one-to-one tutoring, and communication equipment. Because they do not receive funding targeted towards these students they are only able to refer these calls to parent support groups in their service area.

MRC-IL received additional funding in FY00 which allowed for two ILC’s in the southeastern and central regions to do outreach in public schools in their geographic areas. The outreach is being directed toward students with severe physical disabilities and will provide such services as independent living skills training, peer counseling, and self-advocacy training. Additional funding of \$200,000 in FY01 will provide for two additional ILC’s to provide outreach in other geographic areas throughout Massachusetts.

### **Expansion For Supported Living:**

The number of supported living referrals will rise to an estimated 14 in FY’01, due to the increased TAP skills training described above. Students who receive independent living skills training while in school will be more prepared to live independently and develop more self-confidence to make better decisions about their lives. Additional funding will provide for more case coordinators and pay for administrative costs associated with expanding supported living case coordination services to more consumers. Without expansion of these services, many consumers who would otherwise move independently into an apartment after graduation would have to return home or transfer to an expensive skilled nursing facility. Additional funding of \$176,400 is being requested for FY01 to accommodate the rise in SL referrals.

### **Expansion for TAC Assigned Cases:**

The Turning 22 expansion budget also includes funding for 28 non-VR cases previously assigned through the Transitional Advisory Committee (TAC), which are now administered through local VR offices and paid for (*inappropriately*) through federal funds at a cost of \$860,000. With new funding, these cases will be transferred to MRC-IL where they will be administered and paid for through state IL funds. For FY00 and FY01 we expect 3-5 **new** TAC assigned cases each year at an annual cost of \$175,000 (total = \$350,000.) The budget also includes a full-time program coordinator who began working in mid-September to administer these cases; this newly hired staff person has expertise in neuro-behavioral issues which helps him to manage these difficult cases, as well as coordinate with other EOHHS agencies which have joint consumer responsibility. Without \$1,030,000 expansion to fund these TAC assigned cases, they would remain in the local VR offices; these consumers have day/vocational needs that are not appropriately VR responsibility as they have been found ineligible for VR services.

### **Expansion of T-22 SHIP Services:**

Also included in the Turning 22 expansion budget are increases to reflect the needs of 688 consumers in the Statewide Head Injury Program. The funds are in the 4,000 account and will be spent by SHIP (6,000 account) as needed. In FY00, SHIP is funding consumers who will need 24 hour staffed residences and SL case management at a total of \$185,000. In FY01, SHIP will need \$450,000 for 6 new consumers of whom four will require residential services and two will need SL services.

### **Administrative Support:**

Presently the T-22 Program is run by a grade 21 program coordinator, a grade 15 case coordinator, a part-time federally funded M-6 manager, a part-time (unfilled) MO1 case manager, \_ time federally funded administrative assistant, and \_ time federally funded fiscal clerk. An increase to reflect administrative support has been built into the expansion budget since the above federally funded positions also need to be supported by state funds for duties performed under the state account. For the first time, this program will be able to provide for all administrative costs, which were previously supported by a federal grant. A request for \$36,549 in FY01 is being made to cover a portion of these costs for the T-22 Program.

## Justification of Expansion Budget:

<i>FY99</i>	<i>FY00</i>	<i>FY01</i>
	TOTAL: \$485,788	TOTAL: \$1,917,949
\$200,000 additional funding in FY99 being spent for case coordination to 6 new consumers; adaptive housing & other necessary ancillary services for existing consumers. SHIP is initiating funding for five Turning 22 consumers for residential services, staffed apartments, supported living, and family supports.	<p>1. Four new consumers referred for SL coordination.</p> <p>2. Four new TAP positions to fund two additional ILCs to do outreach in public schools.</p> <p>3. SHIP expansion for T-22 SHIP consumers includes consumers who will require 24 hour staffed residences as well as consumers who will need SL case management.**</p>	<p>1. 27 existing TAC assigned cases from VR @ \$860,000.</p> <p>2. Four additional TAP positions to fund two new ILCs to do outreach in public schools @ 50,000/ILC/year = \$200,000.</p> <p>3. Five new TAC assigned cases from VR @ \$31,000/case=\$155,000.</p> <p>4. Fourteen new consumers referred for SL case coordination. @ \$12,600/case = \$176,400.</p> <p>5. A portion of T-22 administrative personnel costs to be covered through state funding=\$36,549.</p> <p>6. A pilot program for 10 new consumers who have severe learning disabilities and do not meet DMR/DMH eligibility, @ \$4,000/cons./year=\$40,000.</p> <p>7. \$450,000 for T-22 SHIP consumers which includes services for approximately 6 new consumers (4 residential, 2 supported living).**</p>

\*\*T-22 SHIP consumers enter residential or supported living programs at scattered times throughout the fiscal year which will reduce “annualized” amounts for these years.

## **Improved Program Outcomes:**

Increased funding will allow an increased number of individuals to receive the benefits of ongoing skills training in the school systems, as well as increasing case coordination services to more Turning 22 consumers with physical disabilities. The results of these services include but are not limited to:

- \* Decreased hospitalizations
- \* Decrease in number of individuals who meet eligibility criteria who must remain or be placed in costly institutional settings
- \* Prevention of evictions
- \* Increased vocational participation and employment of these consumers

The new consultant position to administer and fund non-VR cases assigned through TAC will ensure better coordination and managing of difficult cases.

## **Medicaid/FFP**

There is reason to believe that case coordination services, in all or in part, may be appropriate for Medicaid/FFP.

## **Turning 22 Consumer Profile #1:**

J.D. is a 23 year old man with a diagnosis of Duchenne's Muscular Dystrophy (*MD*) who lived at Massachusetts Hospital School in Canton until he left in 6/98 to move into an independent living situation in Marshfield. J.D. has limited use of his hands and no use of his legs; he uses an electric wheelchair for mobility, and needs a vent 24 hours/day for oxygen and positive pressure air. It is extremely rare for consumers on vents to live independently in the community, as their medical needs are very complicated, but many supports were built into his program to insure success.

J.D. has two live-in personal care attendants, as he was approved for the maximum number of PCA hours, which were needed, because of his medical and other needs. He also receives 6 hours a week of case management through one of our vendors in the Turning 22 Supported Living Program, to help him with problem solving, managing his finances, medical management, etc. Our program also financed a temporary ramp for the unit so J.D. and his roommate (*who also has MD*) could move into the unit in June; in addition, we helped fund a generator to be used as a back up for J.D.'s ventilator in case of a power outage. The Department of Housing & Community Development funded other modifications to the unit, including widening doorways and building two permanent ramps.

Using the independent living philosophy of consumer control and empowerment, J.D. directs all his own care and asks his case manager to assist him with areas he has difficulty with. He is very happy living in the community and is learning how to negotiate the Marshfield streets and shops. He has good computer skills and may someday be able to use these skills vocationally. Being able to move out of Massachusetts Hospital School into an apartment has given J.D. increased self-confidence and a belief

in himself; in addition this situation is much more cost-effective than if he were to move to a nursing home.

## **Turning 22 Consumer Profile #2**

M.K. is a 24-year-old woman with a diagnosis of cerebral palsy. She uses an electric wheelchair for mobility and lives independently in an attractive subsidized apartment in Newton. M.K. receives about 52 PCA hours/week for medical and personal needs, and now has a live-in PCA who is very helpful and accommodating.

M.K. has had many problems adjusting to a more independent living situation, as she previously had lived in a transitional setting that took care of nearly all her needs. When that program closed down, she was referred for Turning 22 supported living services; she now is provided 6 hours/week case management through our Boston vendor to help with time management, hiring/firing PCA's, budgeting, and other needs she feels are important to help her live independently. However, because of many stresses in her life, including the loss of a roommate who previously had helped her and been a friend, she began "acting out". She was unreasonable with her PCA's and parents, couldn't complete the courses she was taking at the local community college, and continued to decompensate.

M.K. had several hospital admissions for psychiatric problems, and was put on anti-psychotic medication. For a while it looked like she might not be able to remain in the community. However, M.K.'s case manager was able to help her through this difficult time by making some recommendations that M.K. responded to. The case manager helped M.K. locate an excellent PCA who has also become M.K.'s friend, which alleviated her loneliness. In addition, a day program was begun which taught her some computer skills, and put her in touch with peers and friends, something she desperately needed. M.K. has temporarily stopped the college courses, which were too stressful, but is now working with her vocational rehabilitation counselor to return to the community college and hopefully receive more supports. She is happy in her apartment, feels more successful, and the psychiatric issues have not returned in over a year.

## **Turning 22 Consumer Profile # 3 (SHIP Consumer)**

JR sustained a traumatic brain injury at age 13, when struck by an automobile as a pedestrian in 1991. JR remained in a coma for 11 days and was discharged from the hospital to a rehabilitation center where he remained for 6 months. He was then discharged home. Problems arose when JR attempted to re-enter school. (JR had a learning disability previous to the TBI.) He experienced lowered frustration tolerance and more outbursts. He was admitted to a residential school for a short period of time and was then transferred to a rehabilitation center in New Hampshire due his increase in behavioral problems.

JR requires a supervision level of 1:1 in the community and 1:2 in the residence. When agitated, JR requires 2 staff to insure he is safe and at times he has needed physical restraint. JR needs supervision around most aspects of his life including ADL's, educational, vocational, and group activities. JR functions best with a behavior plan that is integrated into all aspects of his life. A behavioral plan and point plan is used in all settings he is involved in (i.e. vocational, school, residential, social, and

volunteering). Behaviorally, when frustrated, provoked, or agitated, JR will engage in self-abuse (hitting and biting himself). He will also threaten physical harm to others/self and engage in property destruction. JR has a seizure disorder with an average of 1-2 seizures per month. JR's mobility is not a problem, but he does walk slowly and with an unsteady gait. JR has done well in his current residential school placement as long as behavioral planning and supports have been in place.

### **Consumer Profile # 4 (TAC Assigned Case):**

John is a 24 y.o. single male who currently lives in an out-of-state residential program. He has a history of hyperactivity, obsessive compulsive behaviors, aggression, and sexual acting out toward staff, peers, and animals. He has had multiple hospitalizations and psychiatric diagnoses. He is deaf, and communicates by sign language. He has limited stress and frustration tolerance, poor judgement, poor self-control, and little insight.

John needs a staff secure (4:5 ratio) program, and is living in an out-of-state facility because there is no appropriate program in Massachusetts. Per assignment by the Bureau of Transitional Planning five years ago, DMH, DMR, and MRC-VR are cost sharing. It is the responsibility of MRC-VR to fund the day portion of his program, but since the services are not vocational, VR is inappropriately funding these services. This is an example of a case that should be transferred to MRC-IL where it would be administered and paid for through T-22 IL funds.

**3. 4120-4000      Adult Supported Living Services**  
**FY 98 Funding: \$291,312**  
**FY '99 Funding: \$298,098**  
**Current FY'2000 Funding: \$ 555,766\***  
**FY '01 Proposed Funding: \$1,223,066**  
**Total 1 Year Increase from FY'2000: \$667,300**

\*Includes salary reserve of \$6,293

The Supported Living Program provides ongoing case coordination services primarily to adults who need the assistance of PCA's in order to begin or maintain living independently in the community. These consumers have severe physical disabilities in combination with cognitive, emotional or other functional limitations to independence. They are ineligible for services from DMR, DMH, and the MRC SHIP program and have inadequate family or other supports to meet their needs. MCB currently has no funding and is not requesting funding for a comparable service for individuals with a disability of legal blindness in addition to a severe physical disability. Adults in this program are too old to be eligible for supported living under the Turning 22 program and may not even have been disabled before age 22, but essentially receive the same type of case coordination described in the Turning 22 program. In addition to the above described population of PCA users, there are many individuals whose disabilities do not result in a need for that level of physical assistance, but who, nonetheless, are unable to manage their day to day affairs, and are also ineligible for comparable services from other state agencies and programs. This population includes persons with learning/cognitive

disabilities and less severe physical disabilities. The average consumer in both groups requires four hours of case coordination per week in order to stabilize the PCA system (when relevant), financial management, housing, health care and other essentials of continued independent living in the community.

<u>Increase from FY '98</u>	<u>Total Expansion from FY 98</u>
FY '99 \$ 6,786	\$ 6,786
FY '00 \$ 251,375	\$ 258,161
FY '01 \$ 667,300	\$ 925,461

## **Reason for Expansion**

In FY' 00 additional funding became available to the program through a reallocation of existing funding in the 4000 account to more accurately correspond with areas of need. This is allowing the number of consumers served to increase from approximately 35 to approximately 60. At least half of this growth is coming from consumers who have been on the waiting list for anywhere from a few months to several years: thus the ability to expand the program has been a long time coming. Providing supported living services to consumers at a cost of approximately \$10,000 per year is far more cost effective for the state than the cost of institutionalization (at approximately \$65,000 per year).

Changes in the administration of Medicare and MassHealth programs are shifting more individuals from home health aide services to PCA services. We are seeing, therefore, a greater number of individuals who must use PCA's to remain in the community but are unable to manage them without case coordination assistance. Therefore, the number of individuals seeking supported living case coordination services can be expected to continue to increase.

It is relevant to note here that in FY '99 a 2 year federal grant was obtained from HUD to provide similar case coordination services to 20 individuals statewide who were homeless at the time of referral. The grant enabled these individuals to successfully seek and then maintain living situations in the community. The HUD grant will expire on March 31, 2001 (FY '01). Without some means of continuing supported living case coordination services to these twenty individuals, it is safe to say that most or all of them will be unable to maintain themselves in the community. This will result in twenty individuals, all of whom have severe physical disabilities and rely on PCA's and case coordination, becoming homeless and being evicted to unsafe shelters, costly institutions, or the street.

## **Justification of Expansion Budget**

The following can serve as an easy reference detailing exactly where and how expansion funds are to be used for the services portion of the expansion budget. The actual expansion request also contains funding for salaries and overhead.

FY '01: The budget calls for five areas of expansion, as follows:

- an additional \$200,000 to serve an additional 20 consumers.
- an additional \$ 50,000.00 to ensure continuity of services for the 20 consumers currently served under the federal HUD grant which will end on March 31, 2001. Otherwise, these individuals will be at great risk of returning to homelessness.



- an additional \$290,000 to serve 29 adults who continue to be supported with Turning 22 funds but who should be 'graduating' to the adult program. Without this funding, they must remain in the Turning 22 program. Many of these individuals are now in their 30's and are living stable lives but continue to need ongoing case coordination services.
- an additional \$77,300 for the conversion of an existing federally funded position with some contract monitoring responsibilities for this program to a state funded full time contract monitor, as well as 25% of a manager's, secretary's and bookkeeper's salary from inappropriately used federal to state funds.
- an additional \$50,000 to cover administrative overhead costs such as rent, supplies, phone, etc. previously and erroneously picked up by Federal funds.

Without expansion funds, the Supported Living Program will do no more than maintain services to the current level of 60 individuals. This would certainly result in the unnecessary institutionalization of some future applicants who would be on the waiting list with inadequate supports to continue living independently in the community. More seriously, it would severely jeopardize the independence; most likely also resulting in institutionalization, of the 20 individuals currently served by the HUD grant when it expires in March 1999. Obviously, institutionalization is a higher cost service and diminished quality of life than community based supports.

### **Medicaid/FFP**

There is reason to believe that case coordination services, in all or in part, may be appropriate for Medicaid/FFP.

### **Improved Program Outcomes**

Increased funding will allow an increased number of individuals (still expected to fall far short of all of those in need) to receive the benefits of ongoing case coordination services. The results of these services include but are not limited to a:

- decrease in hospitalizations
- decrease in the number of individuals who meet the eligibility criteria who must remain or be placed in costly institutional settings
- prevention of eviction

The addition of a contract monitor will ensure continued improvement in the capacity and efficiency of the providers in order to maximize the effectiveness of service dollars.

## **Supported Living Consumer Profiles**

### **Consumer Profile #1**

Bill is a current consumer in Work Inc.'s Supported Living program. He is 52 years old and has lived in his own apartment in East Boston since November 1991. Bill has cerebral palsy marked by severe spastic quadriplegia, atrophy in all extremities, and pronounced scoliosis of his entire body. He has no verbal speech and communicates by alphabet/word/phrase board and speech synthesizer. He uses a power wheelchair and requires assistance for all personal care and daily living activities. Bill was a resident of Tewksbury State Hospital from 1960 until 1979. He then lived at Greenery Rehab from 1979 to late 1991. While at the Greenery, Bill cost the Commonwealth of Massachusetts over \$200,000.00 per year. In contrast, his expense to the state for living in the community is only \$9,400.00 per year for supported living services and \$35,000.00 per year for PCA's .

Bill is approved by Medicaid for the PCA program. He gets 55 hours per week plus a Night Time Attendant every night. He receives 6 hours of case coordination assistance per week. Work, Inc. provides assistance in writing checks for personal needs, paying and sending out bills, going to the bank, scheduling some appointments, filling out forms and speaking on Bill's behalf (at his extensive direction) on the phone with many people and agencies.

Bill is medically stable and takes no medications. He is not currently involved in a vocational program and is extensively involved in the community. He volunteers at the Science Museum, goes to concerts, rides the ferry and attends camp in the summer. Presently, he is planning a trip to Florida.

### **Consumer Profile #2**

Donna has been receiving supported living services for 10 months. The services have already brought about some key changes in her life. Donna was referred for supported living services by the MRC Protective Services staff who, upon investigation after a complaint to the Disabled Persons Protection Commission, found Donna to be the victim of neglect.

Donna is a 38 year old divorced woman who lives with her 14 year old daughter. Because of a disability of progressive Multiple Sclerosis, she is unable to walk. Prior to getting supported living services, she used 8 hours per day of home health aide services paid for by the state at a rate of \$19/hour. She could not begin using PCA's until she had a case manager to assist her with this. Although divorced, Donna's ex-husband still had to help out with her care and her financial affairs, but, somewhat understandably, had tried to limit his involvement.

Donna was in a dangerous situation in a second floor apartment in a building without an elevator. Therefore, she was unable to get outside either in the event of an emergency or simply for day to day activities, such as medical appointments, shopping and errands or attending meetings at her daughter's school. She has significant short-term memory deficits, and so is limited in her ability to manage her own affairs. This kept her from utilizing PCA's prior to utilizing supported living case coordination

services, and from managing her finances. Similarly, she did not have the cognitive ability to find accessible housing and to figure out how to afford it given her particular financial situation. Without supported living case coordination, Donna would have continued to be at risk and also would have placed her daughter at risk. She could not have used PCA's and was not able to move to safer more affordable housing. She was not able to manage her finances and day to day affairs and be an effective parent to a teenager.

With supported living services, Donna has been approved for and has hired PCA's. She now has adequate daily help at a less costly rate than the inadequate number of home health aide hours she received. She is on the waiting list for accessible subsidized housing. Because she has limited her housing search to the area near her daughter's school, this will take a bit longer. However, it is probable that she will move within the next 9 months. Donna's ex-husband and daughter no longer need to do her personal care. With supported living, Donna is able to spend more time parenting her daughter, less time in crises, and to stabilize her health. When she moves to accessible housing, she will have more opportunities to participate in the community.

**4. 4120-4000 Protective Services Program**  
**FY'98 Funding: \$516,745**  
**FY'99 Funding: \$516,745**  
**Current FY'2000 Funding: \$586,500**  
**FY '01 Proposed Funding: \$866,500**  
**Total 1 Year Increase from FY'2000: \$ 280,000**

Protective Services is currently funded at a level of \$586,500 and out of this total, \$80,000 is available for the purchase of direct services. The request for future budget appropriation increases are as follows:

<u><b>Increase from FY '98</b></u>		<u><b>Total Expansion from FY '98</b></u>	
FY '99	\$ - 0 -		\$ - 0 -
FY '00	\$ 69,755		\$ 69,755
FY '01	\$280,000		\$ 349,755

## **Program Description**

The Protective Service Program provides protective services to adults with disabilities who have been abused or neglected by a caretaker. This function is mandated to the agency by Massachusetts General Law 19C. Under this mandate, the Protective Service Program has conducted an average of 250 investigations of alleged abuse per year during the last five years. In addition to conducting investigations, the program has provided post-investigative services to individuals who have been found to be at risk for further abuse. As a result of these investigations, Protective Services has identified 100 individuals, each year, who have been seriously injured as a result of abuse and were in need of services. Those individuals were assigned to protective service workers who conducted in-

depth assessments of the violent situations and provided post-investigative services. In addition, there are approximately 55 cases which are carried over from the previous year. The annual case count is approximately 450.

The services needed by individuals who have been the victims of abuse range from case management services to the provision of emergency shelter for those at imminent risk of serious harm or death if they were to remain at home. In-home services are used most often, such services as increased home health aide services or counseling. Individuals who are out of their home because of increased levels of danger are often utilizing emergency protective service respite while alternatives to living at home are developed. As many as eighteen individuals have used emergency respite services in a given year. There are currently eight staff employed in the program; seven are in Boston and one person is located in Worcester. All professional staff carry ongoing caseloads in addition to conducting emergency and routine investigations. There is a program director, supervisor, and unit clerk. The program functions 24 hours per day/ seven days a week and three staff and an administrator are on call for one week intervals every other week. The program covers the entire state. The available funding for direct services in FY '98 was \$80,000. Approximately \$40,000 of this amount is spent on individuals who are in emergency respite shelters. The remaining \$40,000 was utilized for in-home services to approximately 55 individuals. Approximately 100 individuals received no state-funded direct services.

### **Reason for Expansion**

The Protective Service program has not enough funding to meet the legal mandate of MGL 19c, more importantly it does not have sufficient funding to insure battered men and women are adequately protected. Approximately 50 individuals are being under served by being only offered minimal services. Services, such as respite care, were offered only in the most dangerous situations and then for the shortest period of time due to financial constraints. Protective services has funds sufficient only to fund one individual in respite care for one year.

The average cost to MRC for respite care is approximately \$200 per day. For the last three years the emergency demand for respite services due to the immediate risk of serious harm or death from abuse and neglect, has radically increased. If there is a continued similar level of demand for this service, the budget will be fully exhausted prior to the end of the fiscal year. This will leave no funds to provide services to any individual, regardless of the danger which that individual may face. In addition, the lack of funds, requires staff to spend extraordinary time identifying alternative, less reliable, resources which can be acquired free or at reduced costs.

There has been a severe increase in the level of danger in the investigations referred to Protective Services. This increased level of danger requires more staff time devoted to crisis intervention. In FY 99, the staff in this program conducted 5000 home visits or other substantial protective service contracts. This is a 200 percent increase over the activity level of five years ago.

### **Justification of Expansion Budget**

FY '01: The funds would be used to cover increases in the number of individuals referred to MRC, as well as providing for the cost of home care services, violent men's groups and other similar program costs of \$215,000. Regionalization would continue with expansion to Southeastern and Northeastern Massachusetts. Expansion will require the addition of a clerk and investigator will cost \$65,000. The relocation of staff to these areas will reduce the amount of time and money involved in travel and facilitate improved protective service to these areas.

## **Protective Services Program Consumer Profiles**

The vignettes that follow illustrate the nature and level of abuse that MRC is mandated to treat:

### **PSP Consumer Profiles #1**

In Western Massachusetts, a young woman was sexually assaulted and raped by her father. With the assistance of MRC, she was able to get into a battered woman's shelter, but the shelter could not handle her need for personal assistance. While she was at the shelter, her father killed her pet bird, threatening that she was next. MRC located another facility which had other adults with similar disabilities. A creative solution was found as to how to protect this woman in light of an exhausted protective service budget. Her placement was funded appropriately under Chapter 688 which had funds available for services.

### **PSP Consumer Profiles #2**

In Southeastern Massachusetts, a young woman was the victim of multiple rapes. Trauma experts described her sexual assaults as one of the most sadistic they had ever seen. These rapes occurred on a regular basis until intervention by MRC protective service staff in whom she trusted enough to report the sexual assaults. She was given emergency respite service by MRC, however, her placement used approximately 40 percent of the annual protective service budget. The impact of that expenditure on the overall budget meant that routine services such as day treatment or home care could not be provided to abused individuals who were at a lesser level of risk.

### **PSP Consumer Profiles #3**

In Central Massachusetts, a consumer was referred to MRC who had been spending almost all of her time in a wheelchair due to issues of neglect. At the time of initial hospitalization her legs and other body parts had become infested with maggots and her genitals were infested with ants. After hospitalization, returning her to home probably would have been fatal. MRC had to exert great pressure on the local hospital in order to stall discharge of this person. Had MRC funds been available, the Commonwealth would have had the option of a setting which was safe but less expensive than an acute care hospital bed.

### **PSP Consumer Profiles #4**

In Eastern Massachusetts, MRC provided emergency services to a consumer who had been living in squalor. After the caretaker left him, he was living in mid-winter without heat, running water, food, or any other basic essentials. The individual is now in a semi-independent setting having re-established relationships with his family that his prior caretaker would not allow. At the time of MRC intervention, this individual was at imminent risk of serious harm or death.

## PSP Consumer Profiles #5

In Northern Massachusetts, MRC provided services to a battered woman whose abusive boyfriend beat her, tore the phone out of the wall, and lit her on fire. MRC services were critical due to her isolation and need for homemaking and other services. MRC protective service workers assisted her in working with law enforcement agencies and sustaining her in her home with multiple in-home services. The perpetrator was incarcerated.

**5. 4120-4000      Assistive Technology**  
**FY '98 Funding: Unfunded**  
**FY '99 Funding: Unfunded**  
**Current FY'2000 Funding: \$400,000\***  
**Proposed FY'01 Funding: \$1,050,000**  
**Total 1 Year Increase from FY'2000: \$1,050,000**

This new program would provide funding to individuals with severe disabilities for assistive technology, and vehicle modifications. The individuals served under this account would not be Vocational Rehabilitation clients. There would be no upper or lower age restriction. In order to be eligible for services under this account, an applicant would need to show how provision of services would increase independence in the family or community, may not be eligible for any comparable benefits, and may need to meet a financial needs test.

**\*In the current fiscal year, a one-time expenditure of approximately \$375,000-\$400,000 will be made for assistive technology. These funds are available from a reallocation of funds in the 4000 account for FY'00 and additional funds will need to be allocated in FY'01.**

<u>Increase from FY '98</u>		<u>Total Expansion from FY'98</u>
FY '98	\$-0-	\$ -0-
FY '99	\$-0-	\$ -0-
FY '00	\$-0-	\$ -0-
FY '01	\$1,050,000	\$1,050,000

### Reason for Expansion

There is currently \$140,000 of Federal funds available per year to serve the population described above. The program has been virtually level funded for many years, while the cost of assistive technology continues to rise and thus the number of individuals who can be served each year continues to decrease. Equally as important, the range of assistive technology available increases at a phenomenal rate, thereby potentially increasing the independence of individuals with disabilities in many areas of daily life. Without even conducting outreach to make the availability of assistive technology services known, there is a waiting list of anywhere from two to five years for services across the state. It is anticipated that the proposed FY 01 funding would primarily be used to serve those individuals already

known to MRC. As the number of children with severe disabilities being mainstreamed increases, and as the number of elders with disabilities also increases, there can be expected to be an ever increasing demand for assistive technology (including but not limited to vehicle modifications, non-structural home modifications such as the installation of stair glides, and adapted computer equipment) to enable individuals to remain at home or to be discharged from rehabilitation and nursing facilities.

The proposed funding will be used for (1) vehicle modifications to enable people who use wheelchairs or scooters to load the equipment into a vehicle, enter/exit the vehicle while in the wheelchair or scooter and/or drive the vehicle, and (2) adaptive devices and assistive technology to enable individuals to compensate for functional limitations in mobility coordination, reading, speaking, or cognition.

## **Justification of Expansion Budget**

The proposed funding includes the following components:

Vehicle modifications, adaptive equipment and assistive technology (to serve approximately 130 consumers)	\$910,000
o Salaries for 2 FTE's for program admin.	\$ 90,000
o Administrative overhead costs	\$ 50,000
Total FY'01	\$1,050,000

It is not anticipated that any items contained in this proposed line item would be FFP or Medicaid reimbursable.

Provision of services described in this new program would benefit individuals by increasing their independence and thus, their ability to live at home, as opposed to being placed in a residential school or a nursing home/long term care facility. The services would also decrease the reliance on and expense of Medicaid funded transportation and possibly home health care.

## **Assistive Technology Consumer Profiles**

### **Assistive Technology Consumer Profile #1**

Rosa is a 50-year-old single woman who lives in her own apartment with the assistance of PCA's. Because of a disability of muscular dystrophy, she uses an electric wheelchair and relies on a ventilator to help her breathe at all times. She is a bright and independent woman who needs assistance in all activities of daily living. Her care and the operation of her ventilator are complex, and it has taken her a long time to find stable PCA's willing to do this care.

Rosa, who receives SSI, was nonetheless able to acquire a used van. She has been using portable ramps to attempt to enter and exit the vehicle. These are not safe. She has fallen off of them at least twice,



disconnecting her ventilator in the process. Hiring a van service for transportation is not an option, as they will not transport her ventilator. When she has used an ambulance, the EMT's have actually relied on her PCA's to monitor and operate her ventilator.

Rosa will be on a waiting list to receive federal funding for purchase of a wheelchair lift for her van for at least five years! She has no other possible funding source to utilize. While she waits, she must live an extremely narrow existence in which she can not go farther than her wheelchair will take her, and can not go out safely at night or in inclement weather. More importantly, she risks her safety every time she uses her portable ramps and van to get to routine medical appointments. Yet, without this medical care, she jeopardizes her health even further.

Rosa neither deserves nor needs to be in a nursing home (at a cost of upwards of \$250,000.00 per year) when the alternative, the installation of a lift in her van, would cost only about \$7,000.00.

## **Assistive Technology Consumer Profile #2**

Ellen is a 38 year old divorced woman who sustained a spinal cord injury seven years ago. As a result of this injury, she has no movement of her upper or lower extremities. In addition, she sustained vocal cord damage which has left her speaking in a raspy whisper. After several years of living with her elderly parents, and a short stay in a nursing home, Ellen was able to move into her own apartment where she manages many hours of PCA services. Nonetheless, she still finds herself alone for several hours a day.

Ellen, formerly employed as a hairdresser, is not interested in getting retrained or in employment at this point in her life. She could benefit from a computer and adapted software but needs funding to purchase it. An evaluation has determined that, despite her speech deficits, Ellen could use a microphone and a Dragon Dictate system. With these adaptations, she would be able to speak commands and text into the computer to compensate for her inability to use the keyboard or manipulate a mouse.

Having a computer that she could use independently would afford Ellen a significantly greater amount of safety when alone and of independence. She could, for example, combine the computer system with other technology to dial her phone, activate her door lock, control lights and appliances, and contact emergency help. She could also use it as a means of producing written correspondence, writing checks, and shopping via the Internet.

It is reasonable to conclude that the procurement of such assistive technology would enable Ellen to live safely on her own, avoid institutionalization and enhance the quality of her life and the range of tasks she could do independently.

**6. 4120-4000      Personal Care Assistance Program**  
**FY'98 Funding: \$825,000**  
**FY'99 Funding: \$725,000**  
**FY'2000 Funding: \$622,000**  
**FY'2001 Proposed Funding \$580,000**

The MRC Personal Care Assistance Program provides Personal Care Services to individuals with disabilities who are employed and need these services to be able to live in the community. All of the 27 clients currently in the program are employed and contribute towards the cost of their own Personal Care Attendants.

The MRC Personal Care Assistance Program has been in operation since 1978 and has served as a model for similar programs throughout the country. Currently, the program is closed to new applicants who are referred to Commonwealth for services. The MRC PCA program uses the same rate and evaluations as the PCA program through Mass Health.

**Justification for Expansion Budget**

As a result of a new Request for Response (RFR) from Mass Health, the rate for PCA services has increased to \$10.74 per hour. This increase would bring all PCA programs in Massachusetts in compliance with Federal and State laws regarding Social Security and Income Tax withholding. In FY'99 client attrition was significant enough to offset the new increases in PCA rates. MRC is not asking for any expansion funds for the PCA program as it is expected that client attrition will continue during FY'2001.

The current average cost for a client in the MRC PCA program is \$19,546.00 per year plus administrative costs including one staff salary.

<u>Increase from FY '98</u>	<u>Total Expansion from FY '98</u>
FY '99 \$ -0-	\$ -0-
FY '00 \$ -0-	\$ -0-
FY '01 \$ - 0 -	\$ -0-

It is anticipated that with client attrition between now and the beginning of the FY '01, No expansion funds will be required.

The MRC Personal Care Assistance Program would not be eligible for any Federal Financial Participation during the FY '2001 budget period. It is unlikely this program would qualify for Federal Financing during the FY '2001-2002 budget cycle.

**7. 4120-4000 Multiple Chemical Sensitivity Outreach Project**  
**FY'98 Funding: \$ -0-**  
**FY'99 Funding: \$ -0-**  
**Current FY'2000 Funding: \$ -0-**  
**FY'2001 Proposed Funding \$225,000**  
**Total 1 Year Increase from FY'2000: \$ 225,000**

<u>Increase from FY '98</u>	<u>Total Expansion from FY '98</u>
FY '99 \$ -0-	\$ -0-
FY '00 \$ -0-	\$ -0-
FY '01 \$225,000	\$225,000

## **Program Description**

There are a number of low incidence disabilities that are emerging into the awareness of the mainstream of the rehabilitation community. At the Forum held in Worcester the Agencies heard from a number of consumers of Multiple Chemical Sensitivity Organizations via the telephone. Their disability prohibits their testifying in person because of their hypersensitivity to chemicals that exists in the normal environment. Chemicals such as fragrances, new carpeting, most cleaning products and the like produce sometimes life threatening reactions.

This project will take on the task of designing and implementing a new service delivery paradigm for this and other low incidence populations. Services such as housing, in-home supports, medical care and other independent living services will be provided to individuals who have in the past have been excluded from accessing services because of the lack of understanding of their disability. In addition, a training curriculum about this condition will be developed and provided to staff in the Agency.

## **Reason for Expansion**

The Independent Living Movement has progressed from addressing the needs of persons with primarily physical disabilities to developing community alternatives for persons with all types of disabilities. Persons with Multiple Chemical Sensitivities are the most recent group to address the Commission with its needs and recommendations for what their community needs are for living more independently in the community. The present IL Service Delivery System at MRC does not have the capacity to address the requested needs of this community as presented at our Worcester Forum.

The new monies requested would allow the Commission to develop a pilot project through a community based program that would address the issues raised by the Multiple Chemical Sensitivities Community. In addition, an advisory committee for the project would be formed of members of this community to ensure that the project truly addresses the IL needs and develops a long term approach to provide statewide services for this constituency. The advisory committee will also assist the project

in developing a training curriculum for Agency staff, which will be conducted to better inform Agency personnel about this very unique disability.

### **Justification for Expansion**

FY' 2001 The \$225,000 requested in this fiscal year fully funds the project to develop and implement a strategy to provide Independent Living Services to persons with Multiple Chemical Sensitivities. The vendor with the continuous input from the advisory committee would implement strategies to address the housing, communications, transportation and other IL needs of this community. The Project would also develop recommendations for making such services available on a statewide basis.

### **Multiple Chemical Sensitivity Consumer Profiles**

- 1. Consumer Alice was exposed to multiple chemicals on her job as a nurse. Her condition began to change slowly at first with a constant allergy. She then began to be hypersensitive to almost all chemicals such as soaps, perfumes, any type of carpet and even clothes.*

She ultimately had to move to a new apartment. But that take almost two years to find because there was no resource to help her locate an accessible apartment which could meet her needs. She tried the housing registry but it did not address her "accessible" needs. On her own she finally found a suitable place to live but during this period of time her condition gradually worsened until she almost died. She was able to recover but cost thousands and thousands of dollars in medical costs because there were not appropriate IL Services in place.

- 8. 4120-4001 Housing Registry Expansion**  
**FY'98 Funding: \$100,000**  
**FY'99 Funding: \$100,000**  
**Current FY'2000 Funding: \$100,000**  
**FY'01 Proposed Funding: \$456,750**  
**Total 1 Year Increase from FY'2000: \$ 356,750**

### **Program Description**

The Housing Registry assists people with disabilities in identifying housing opportunities, including wheelchair accessible and adaptable market rate and subsidized housing across the Commonwealth. Beginning in 1995, the legislature has provided \$100,000 annually for the operation of the Housing Registry computer database to identify wheelchair accessible units and match them with people with disabilities, families with children with disabilities and elders needing these units. To date, the Housing Registry has listed 1175 apartments statewide, leasing 89% of the units.

**Increase from FY'98**

**Total Expansion from FY'98**

FY 1999 \$ -0-	\$ -0-
FY 2000 \$ -0-	\$ -0-
FY 2001 \$ 356,750	\$356,750

## Reason for Expansion

The \$100,000 in funding currently provided by the legislature supports the administration of the database including gathering the listings and disseminating the information daily to the ten Independent Living Centers (ILCs) across the state. It is the ILCs who identify the potential tenants for these units including conducting outreach, assisting with applications, identifying support services and other key tasks in the move to a new home. As the Housing Registry has become more and more successful, the ILCs have received an increasing number of calls from people wanting the housing information and requiring assistance with the application process. ***The ILCs currently receive over 800 calls each month, or nearly 10,000 calls annually! The ILCs currently receive no financial support for providing this increasingly demanded service.***

## Justification for Expansion

FY' 2001 Provide the ILCs with support for their participation in the Housing Registry including dissemination of information and assisting consumers to access housing. Ten ILCs will receive support for .5 FTE and related costs. One ILC will receive support for 1 FTE. Also provide a 5% COLA to CHAPA (Citizen's Housing and Planning Associates) who manage the central database to provide for increased administrative costs. They have received no increase since 1995.

The backbone of the Housing Registry is a computer network that is terribly outdated.

A one time award of \$30,000 to allow the 12 satellite offices to upgrade to Pentium computers. This would allow staff to dramatically increase productivity and expedite distribution of time-sensitive information about vacant accessible apartments.

## Housing Registry Consumer Profile

Staff from MRC's Protective Services Program identified a man with a disability who was being abused by a family member and needed to move as quickly as possible. Mr. J needed an accessible apartment with a subsidy and wanted to live in the Lynn area. Accessing the housing registry on-line IL staff quickly identified 3 apartments in Lynn with one bedroom, accessible, affordable units. Mr. J. contacted the housing complex contact person identified on the Registry and moved into a new apartment within 2 weeks.

**9. 4120-4002 Mass. Network of Information Providers**  
**FY '98 Funding: \$ -0-**  
**FY '99 Funding: \$ -0-**  
**Current FY'2000 Funding: \$ -0-**  
**FY 01 Proposed Spending: \$255,000**  
**Total 1 Year Increase from FY'2000: \$ 255,000**

### **Program Description**

The Massachusetts Network of Information Providers is a network of 28 local and regional service providers that are connected together by computer. The data they provide is collected and distributed by a central location and updated on a quarterly basis for information provided by each member and by providers themselves. These Network members provide individuals seeking information on disability-related programs and services the latest Information and Referral (*I&R*) on such community based programs and services. The Network is presently funded by federal vocational rehabilitation funds but given the broad, non-vocational rehabilitation focus of the information, the program should be funded with state dollars.

<u><b>Increase from FY '98</b></u>		<u><b>Total Expansion from FY '98</b></u>
FY '99	\$ -0-	\$ -0-
FY '00	\$ -0-	\$ -0-
FY '01	\$255,000	\$255,000

### **Expected Population Growth**

The present Network provides Information and Referral at the rate of 3500 calls/quarter to individuals with disabilities or others who need such information. Through the Network individuals can access information on such issues as what doctor in their area has an accessible office to what agency provides reduced or free meals delivered to one's home. It is expected that the demand on the network will continue to grow at an annual rate of over 30% given the history of the Program. There is also a need to continue to expand the membership of the Network to provide better localization of the information. The projected growth to 40 organizations should occur by FY '2000 and to 60 organizations by FY '2001. The ability to grow the network allows for more accurate information because the I & R specialist has better first hand knowledge of the area.

### **Reason For Expansion**

This demand, if not addressed, will create real problems in timely access to information that may prevent an individual with a disability from staying in the community or becoming ill because timely treatment is not available. Because the demand for access to Information and Referral is growing at a

rate of at least 30% per year, there is a real need to address any such increase in I & R requests. There has been a significant shift in the policy of the Commonwealth to deinstitutionalize persons with disabilities. This change in policy has created a greater need for access to information about community based services. In fact, it can be said that because of the existence of the MNIP, the ability of the Commonwealth to respond to the policy shift has been enhanced. Clearly any slow down in access to I & R will create problems that could lead to reinstitutionalization, health problems, rehospitalization or increase in admittance to chronic care hospitals.

### **How Funding Will Be Used**

The first year of funding will be used to continue operation of the Network with state funds which, given the scope of the Network's I&R, are more appropriate. The second and third year funding expansion would cover the costs of new technology, training, software upgrades and the addition of new staff at primary provider's information collection headquarters. Additional I&R Specialists at some of Network sites would also be added as needed.

### **Justification of Expansion Budget**

The new funding for the base is proposed to replace the present federal VR funding because the scope of the MNIP Network is now beyond the limited propose of the federal mandate of Title I funding. In years 2000 and 2001 the expansion was derived by taking into account the acceleration of the number of calls to each site and the proposed expansion to up to 60 members of the Network by 2001. The costs for the expansion each year include: new staff at the data collection headquarters; new software; training and technical assistance; additional I & R specialists at selected new and existing sites depending on demand.

### **Improved Program Outcomes**

Additional monies will be used to fund extra staffing needed to expand the MNIP network. This will entail additional training, support, software, and equipment. The additional funding will also be used to expand the I & R database and to institute a systematic quality enhancement program. Some supplementary funds will be used to supplement the I & R Specialists in certain existing and new locations. Lastly the expansion to up to 60 members of the Network will allow the information to be more localized and therefore more timely and more accurate.

### **MNIP Consumer Profiles**

Consumer #1 needed a new leg brace but did not know how to get funding for the brace. After calling the MNIP he was assisted in accessing Medicare which ultimately covered the cost of the device. He also received assistance in getting a referral to an orthotic consultant who fitted the consumer for the brace.

Parent #2 called their local MNIP office seeking assistance in accessing recreational activities for their son who lives in a community residence. They had been trying for years to address the problem but met with little success. After only a few calls to the Network office they were able

to locate a local organization to help them arrange meaningful recreational activities that significantly improved their son's quality of life.



**10. 4120-7997      Home Modifications Program**  
**FY'98 Funding: Unfunded**  
**FY'99 Funding: \$2,000,000\***  
**Current FY'2000 Funding: \$1,200,000\***  
**FY'01 Proposed Funding: \$3,000,000**  
**\*FY'99 funds were rolled over to FY'00 to expend**

### **Program Description**

The Home Modification Program will provide loan guarantees and interest rate subsidies to elders, families with children with disabilities and adults with disabilities to make access modifications to their homes. Eligible types of modifications include ramps, bathroom modifications as well as more modest modifications such as grab bars.

In the 1998 Emergency Capital Appropriation Bill, the Governor approved the bonding of \$10 million in funds for this program. As of this writing, the program has not been allotted the Capital Allocation or "cap" needed in order for the Administration to move forward with this important program.

<u><b>Increase from FY'98</b></u>		<u><b>Total Expansion from FY'98</b></u>
*FY 1999	\$2,000,000	\$2,000,000
*FY 2000	\$1,200,000	\$3,200,000
*FY 2001	\$3,000,000	\$6,200,000

\*Note: Funding is bond funding; allocation of "cap" is needed in order to use the appropriated funds.

In June 1999, a CAP was approved allocating \$2.0 million in bond funds to be "rolled over" into FY'00 to provide deferred payment and low interest loans to qualified homeowners. MRC has entered into contract with CEDAC (Community Economic Development Assistance Corporation) to administer the loan funds. CEDAC contracts with 6 regional housing providers, who conduct intake, assess need and process loans. It is estimated 200 individuals with disabilities, elders and families with children with disabilities will benefit from these funds in FY'00. MRC will work with EOHHS and Administration and Finance to identify an additional \$1.2 million in bond funds in FY'00 to be used towards the end of FY'00 or rolled into FY'01. It is anticipated that through community outreach there will be a waiting list for this important program by the end of FY'00.

### **Reason for Expansion**

The Governor and the legislature established a home modification program in order to address the needs of the elders and people with disabilities living unsafely in their homes or unable to return to their homes from high cost institutional settings because of physical barriers. The 1990 U.S. Census indicated that 4% of Massachusetts's citizens had a mobility and self care limitation. Using this and other data, the nationally renowned Adaptive Environments Center estimates that over 53,000 Massachusetts residents require some type of home modification. The majority of these are on fixed,

low-incomes and require assistance to make these modifications. This unmet need is reflected in the length of waiting lists for the small federally-funded adapted housing program currently operated by MRC. In the Springfield area, for example, it can take up to six years to receive funds for a simple home modification such as a ramp or grab bar.

## **Justification for Expansion**

FY' 2001 Expansion in FY'01 of \$3,000,000 in bond funds is expected to provide home modification for an estimated 300 elderly and disabled households across the state.

## **Home Modification Consumer Profiles**

- John is 15 years old. He uses a wheelchair and has been disabled since birth. He lives with his family in the 2-story home they own in a Boston suburb and his family provides all of his personal care. When he was younger, his parents were able to carry him up and down the stairs to his room and the bath on the second floor. At 15, however, this has become increasingly difficult. His family cannot afford to make the necessary modifications; widen the doorway to a first floor room so he can use it as a bedroom and make the first floor bathroom accessible. Unless these modifications are made, the youth will have to move to the Massachusetts Hospital School at a cost of \$137,000 per year to the State.
- An older man has lived in his current home since he and his wife purchased it many years ago and his wife recently passed away. He cannot safely use the stairs and must start to live on the first floor. This requires the addition of a door or partition to create a private space in the living/dining room and grab bars in the first floor bath. These modifications combined with home care services will allow him to remain safely and comfortably in his home and prevent a move to a nursing home at an average annual cost of \$127,750.

**11. 4120-5000 Home Care Assistance Program**  
**FY'98 Funding: \$3,966,066**  
**FY'99 Funding: \$4,500,368**  
**Current FY'2000 Funding: \$4,588,569 (includes salary reserve)**  
**FY '2001 Proposed Funding \$5,488,569**  
**Total 1 Year Increase from FY'2000: \$ 900,000**

## **Program Description**

This account provides Home Care services consisting of grocery shopping, meal preparation, light cleaning and washing laundry for individuals with disabilities, ages 18 through 59, who live alone or with minor children under the age of 18. Failure to access these services would result in increased

hospitalizations and possible institutionalization of consumers. These services allow the consumer to continue to live in the community.

**Increase from FY '98****Total Expansion from FY '98**

FY '99	\$ 595,000	\$ 595,000
FY '00	\$ 88,207	\$ 683,207
FY '01	\$ 900,000	\$1,583,207

**Reason for Expansion**

MRC Home Care Assistance currently serves 1,740 clients with Homemaking services, an increase of over 300 clients since FY'99. Additional 275 eligible clients were on the processing list to be determined for eligibility for these services. While some clients can be reached due to attrition. The additional funding from the FY'2000 budget only allowed for salary reserve and no additional clients. It usually takes a minimum of 2 to 3 months on the processing list before a client can be determined eligible and begin to receive services. Even with this shortened time, a number of the clients on the waiting list no longer need the service as their disabilities have worsened, they have passed away, moved out of state or been placed in an institution. Since 1990, annual appropriations from the legislature have been level, except for FY'99, when an additional \$595,000 was added. This has been very helpful in reducing the processing/waiting list, however the processing list continues to grow as new intakes are received daily.

**Justification for Expansion Budget**

Allowed for the reduction of the client waiting list to 157, as well as funded two case manager FY '99: The increase of \$595,000 dollars of funding to the existing appropriation has positions to coordinate services for these clients newly retired off of the waiting list.

FY '00: The additional amount of \$88,207 only allowed for salary reserve for the lowest paid direct care workers and did not fund any additional clients into the program. Rate increases for homecare vendors are being approved by the Department of Elder Affairs. MRC uses the same rates as the Department of Elder Affairs.

FY '01: The increase in funding of \$900,000 would provide additional monies to cover the annualization of the clients who have come off the processing list. Also provide sufficient funds to handle a number of new applicants expected, as well as covering the increased costs of providing services due to rising homecare service rates for each provider.

**Federal Financial Participation:**

The MRC Home Care Assistance Program has become eligible for Federal Financial Participation (FFP) during the FY '99 budget period. MRC developed a plan to capture actual FFP funds and has generated \$2.2 million dollars in FFP, since June 1998, back to the Commonwealth, covering the period April 1996 through March 1998. It is estimated that approximately \$1.7 million dollars in FFP, will be captured, annually for the Commonwealth, by the MRC Homecare program. Prior to FY'2000, all of these funds reverted to the general treasury of the Commonwealth. With the establishment of a retained revenue account (4120-5050) in FY'2000,

a portion of the monies earned from Federal Financial Participation (FFP) can be earmarked for programs in MRC, including Homecare Assistance. More detail can be found in the 4120-5050 section.

## **Home Care Assistance Program Consumer Profiles**

### **HCAP Consumer Profile #1**

J.F. is a 51-year-old female consumer, of the Western Massachusetts region, who after seven failed back surgeries developed failed back syndrome, a condition characterized by constant, chronic pain throughout her back and spinal column. As a result of this diagnosis, which left her functionally limited in areas such as sitting, standing, walking, bending and lifting. J.F. applied to the M.R.C. Home Care Assistance Program in desperate need of a home care worker to assist her with daily living skills such as cleaning, shopping, meal preparation and laundry.

Throughout the three years J.F. has had home care assistance, her physical and mental health have significantly improved. Home care assistance has had the direct causal effect of alleviating her constant, chronic back pain. Consequently, she was able to start working full-time as a psychiatric nurse practitioner assisting the elderly in several different nursing homes and institutions. Ironically, without the Home Care Assistance Program she would still be a prisoner in her home or a resident in a nursing homes. Home care services have had the effect of reconnecting her with a society she was formerly alienated from by her disability. It is society that now reaps the benefits from her skills and liberated aspirations.

### **HCAP Consumer Profile #2**

V. S. is a 43-year-old single woman who has been receiving homemaking services through the Home Care Assistance Program since November 1988 (9 years). She lives in an accessible three-room condominium condo, which she rents. She is on Social Security Disability and on Medicare.

V.S. has been disabled since 1984 when she was diagnosed with Amyotrophic Lateral Sclerosis (ALS), a progressive neuromuscular disease with no known cure. V.S. has severe spasticity, which is the primary symptom of this disease. She is unsafe ambulating, although in her environment she functions adequately enough. She uses a walker in her apartment and a wheelchair outside. V.S. is not able to maneuver the wheelchair without assistance, as another symptom of this disability is weakness. This makes it very difficult for V.S. to hold or control things with her hands. Her ability to grasp, hold, or push is almost non-existent. It is very difficult for her to open the door to let people inside her apartment or even hold a pen to write.

In addition to the above limitations, V.S. has problems with her speech, which is dysarthric. She is extremely difficult to understand and it takes her a long time to pronounce a word, almost to the point where you might think she is in a lot of pain.

On the positive side, V.S.'s cognition and vision are good and the way she deals with her disability is very admirable. She is a very pleasant person with a very nice personality. She has a

very good sense of humor and likes to tell jokes. V.S. works well with those who allow her decision making and respect her need for control of her environment.

V.S. is currently receiving 4 1/2 hrs. of homemaking services through the Home Care Assistance Program for grocery shopping, laundry, and cleaning. She also needs help with meal preparation and personal care. These needs are being met by another agency.

If V.S. were not receiving homemaking services through the MRC Home Care Assistance Program and home health aide and nursing services through another agency, she would be able to continue to live in the community.

### **HCAP Consumer Profile #3**

Frank is a consumer receiving services from the MRC Home Care Assistance Program. The MRC Vocational Rehabilitation Division in March 1997 referred him to Homecare. Frank has a spinal cord injury with incomplete C6 quadriplegia and a history of muscular dystrophy, which severely limits his mobility at home and outside of the home. He uses a walker in his home and a wheelchair outside. Frank's ability to lift, bend or use his upper or lower extremities is severely limited and he has poor stamina. MRC Homecare is providing 5 hours per week of Homemaking services including grocery shopping, meal preparation, and laundry and cleaning. With this service provided by MRC Home Care, Frank has been able to achieve his Vocational Rehabilitation goals and return to work.

### **HCAP Consumer Profile #4**

Stephen is a 45-year-old male who has had two traumatic brain injuries in 1978. He has severe memory deficit and unsteady gait causing frequent falls and he is often unable to realize his own needs. He has seizure disorders, hypertension and cellulitis, which developed in 1996, causing open sores on his legs. When Stephen was referred to the MRC Homecare Assistance Program in 1995, he was living in a bug-infested apartment with feces on the bathroom walls and he was at risk for continued infection on his legs due to unsanitary conditions. He was quite paranoid, had six locks on the door and was at risk of eviction from his apartment and eventual institutionalization. His meals consisted of cookies and opened cans of food. His hand was seriously burned by hot grease while trying to prepare a meal. Stephen was evaluated by MRC Home Care as requiring 6 hours of homemaking services per week. In addition the apartment manager arranged to have Stephen's apartment receive a heavy cleaning to eliminate the unsanitary conditions.

Two and one-half years later Stephen is still in his apartment and are on good terms with the housing authority, which had in prior years tried to evict him. MRC Home Care and its vendors have worked with Stephen and other care givers to help him overcome many obstacles in relation to accepting help and maintaining his independence in his home. He now does his own food planning with his homemaker who shops and prepares meals in advance. His home is currently well maintained with Stephen's eager participation. His basic ADL's and self-esteem have improved tremendously along with his independence.

**12. 4120-5050 Home Care Retained Revenue Account**  
**FY '98 Funding: \$ 0**  
**FY '99 Funding: \$ 0**  
**Current FY'2000 Funding: \$1,000,000**  
**FY '01 Proposed Funding: \$2,000,000**  
**Total 1 Year Increase from FY'2000: \$ 1,000,000**

The Home Care Assistance Program began generating federal financial participation (ffp) in 1998 by getting reimbursement for eligible Medicaid recipients. This process was recognized by the Great and General Court in this year's budget deliberation process. The Legislature determined that MRC should have access to up to \$2,000,000 of this money by establishing a retained revenue account, 4120-5050.

<u><b>Increase from FY '98</b></u>	<u><b>Total Expansion from FY '98</b></u>
FY '99 \$ -0-	\$ -0-
FY '00 \$1,000,000	\$1,000,000
FY '01 \$2,000,000	\$3,000,000

**Program Description**

Unlike other programs, the Retained Revenue Account does not have a specific program description. Rather, this resource can be used to supplement the needs of the Home Care Assistance Program and other Agency needs as determined by Program demands. It has been determined this year that the \$1,000,000 available for FY '00 will be used as follows:

- Up to \$350,000 for the Home Care Assistance Program to cover the costs of additional consumers in the Program;
- Up to \$650,000 for Turning 22 consumers assigned to the Agency by the TAC (Transition Advisory Committee). These consumers are presently being funded by federal VR funds but this is not appropriate given that none of the persons in programs meet the employment goal requirement of federal law.

It is hoped that the costs of the Turning 22 consumers mentioned above will ultimately be funded in the appropriate accounts (4120-4000 for non brain injured consumers and 4120-6000 for brain injured consumers). The concern is that funding any type of on going needs in the retained revenue account would annualize into escalating costs that would quickly consume the entire account.

The Agency is also working on the development of other revenue streams from Supported Employment and Brain Injured Services through SHIP. It is hoped that these resources will also be authorized to contribute their revenue to this account when funding begins to occur.

- 13. 4120-6000      The Statewide Head Injury Program**  
**FY'98 Funding: \$6,682,667**  
**FY'99 Funding: \$6,691,328**  
**Current FY'2000 Funding: \$6,785,820\***  
**FY'2001 Proposed Funding: \$24,950,820**  
**Total 1 Year Increase from FY'2000: \$18,165,000**  
**(\*includes \$82,180 in provider salary increases)**

## **Program Description**

The Statewide Head Injury Program (*SHIP*) works collaboratively with other professionals and organizations both within and outside the Massachusetts Rehabilitation Commission with the intent of sharing information, expertise and resources which will further the availability and access to specialized services for people with traumatic brain injury (*TBI*). Service coordination staff work with consumers and families to assist them in planning, obtaining and coordinating the programs and services they need. Technical assistance and training is provided to professionals in the public and private sector, school systems and special educators, families and consumers. Many of these efforts are geared toward developing the skills and knowledge necessary to better serve people with TBI at a local level.

SHIP places a high priority on program development. The focus has been on a statewide network of programs that address the unique needs of this population. The range of services and programs now available to SHIP eligible consumers include, but are not limited to, community integration programs, long-term employment supports, community-based residences and supported living services, therapeutic recreation, substance abuse treatment, and neurobehavioral programming. The final component of SHIP is the ability to purchase ancillary support services for individuals in order to help avoid institutionalization and maintain people in community settings. These services are as diverse as those we serve and are highly individualized. Some examples of ancillary services are adaptive equipment, homecare, respite, transportation, cognitive retraining, protective services, family supports and specialized evaluations.

As SHIP services have evolved over the past fourteen years, the system has considered the needs of consumers of all ages, including children, those turning 22, the aging population and the elderly. The challenge now is to develop a network of linkages and services to satisfactorily address this broad base of constituent needs.

<u><b>Increase from FY '98</b></u>	<u><b>Total Expansion from FY '98</b></u>
FY'99 \$     - 0	\$     - 0 -
FY '00 \$     - 0	\$     - 0
FY '01 \$ 18,165,000	\$ 18,165,000



SHIP has had more than 3,100 applicants since it began to provide services to brain injury survivors and their families in July, 1985. The majority of these adults live at home with their aging parents and receive limited or no services.

## **Reason for Expansion**

Over the years, SHIP has been successful in leveraging a tightly constrained budget and serving up to 500 survivors each year. However, these services tend to be ancillary supports and not the long-term services survivors need such as housing supports/supervision, functional skills training; meaningful daytime or leisure activities, transportation to local resources/activities/ services; and community support services to allow them to remain in their homes and communities living as independently as possible. The minimal “expansion” funds received to date have been used for provider salary increases and to meet legislative requirements to provide funds to specific programs.

The demand for SHIP services continues to grow as we receive an average of 20 - 25 new referrals each month. A large number of consumers and families would benefit from additional appropriations over the next year which would allow SHIP to develop and provide these necessary services. In order to implement this initiative SHIP will need to increase their service coordination staff who are responsible for working with these additional consumers and families to identify, access and monitor their individualized service needs. A minimum of 10 FTE’s will be hired to assist in reducing the SHIP waiting list through this increased funding.

## **Community-based Housing**

\* In the area of twenty-four hour supervised community-based residential and supported living programs, \$8,400,000 is proposed which will serve approximately 40 people in highly supervised settings and 200 individuals in supported living settings.

<b><u>Increase from FY ‘98</u></b>	<b><u>Total Expansion from FY ‘98</u></b>
FY ’99 \$ - 0 -	\$ - 0 -
FY ’00 \$ -0-	\$ - 0 -
FY ’01 \$ 8,400,000	\$ 8,400,000

These estimated costs are based on historical expenditures in this programming area. Supervised residential services have averaged approximately \$100,000 per consumer requiring 1:2 staffing 24 hours per day. Supported living runs close to \$20,000 per consumer which pays for 25 hours per month of case management services. These funds will allow adults with TBI to live as independently as possible in the community and no longer be dependent on aging parents for support and supervision.

It is believed that these services would qualify for FFP reimbursement under a Home and Community-based waiver or expanded Medicaid state plan. MRC is actively working on a TBI

waiver with DMA for submission to HCFA in early FY'00. Revenue generated from this waiver, if returned to the SHIP account, would assist in covering a portion of this needed expansion.

## **Structured Day Programs**

Supervised day activities outside the home are needed by a large number of survivors. Those with severe cognitive, physical and behavioral challenges often require a highly structured setting in order to function and participate within a community setting. Families can not offer these consumers the supervision, consistency and training that is necessary to assist them to become more independent. In addition families are overburdened financially with the cost of caring for this additional family member while often having to give up one income in an effort to insure their ongoing safety and care. The anticipated outcome of making this type of service available is it reduces family stresses, assists individuals in developing skills that will lead to greater community integration, decreases survivor isolation and helps to prevent crisis.

There is a clear need to develop these programs with estimated costs of approximately \$10,000 per participant given, the focus on structure and maintenance rather than active treatment.

Expansion dollars are needed in the following amount:

- \* Four million dollars would allow SHIP to develop and fund this type of service for about 400 individuals

These services might qualify for FFP reimbursement under a Home and Community based Waiver or expanded Medicaid state plan. MRC is actively working on a TBI waiver with DMA for submission to HCFA early FY'00. Revenue generated from this waiver, if returned to the SHIP account, would assist in covering a portion of this needed expansion.

### **Increase from FY '98**

FY '99 \$ - 0 -  
FY '00 \$ - 0 -  
FY '01 \$ 4,200,000

### **Total Expansion from FY '98**

\$ - 0 -  
\$ - 0 -  
\$ 4,200,000

## **Transportation**

Correspondingly, transportation money is needed to allow these individuals to attend these programs. Families do not have the means to provide this service on a daily basis and public transportation is often not an option due to the consumers' deficits. Funding for transportation is therefore being requested as well. The average cost of transportation based on SHIP's past history of expenditures is \$7,000 per person. Once again this service could be considered for FFP reimbursement under the same mechanisms as detailed above. Presently transportation is reimbursed under Massachusetts Medicaid when the individual has a doctor's "order" to go to a medically-based service/appointment. The design of the structured programs would need to be considered in order to tap directly into this available service if no changes were to be pursued in the state plan. This service would also be reimbursable under a HCBW application.

**Increase from FY '98**

FY '99 \$ - 0 -  
FY '00 \$ - 0 -  
FY '01 \$ 2,940,000

**Total Expansion from FY '98**

\$ - 0 -  
\$ - 0 -  
\$ 2,940,000

**Home & Community Supports**

Last but equally important is the need for community-based supports that are provided in someone's home and community focusing on the development of functional and independent living skills as well as out-of-home respite. These ancillary services are highly individualized and may require more than one service for a consumer during a fiscal year. For example, a survivor living with his/her family may be in need of learning how to cook or use public transportation. At the same time he is totally isolated at home, dependent on his family for "social" interactions and may benefit from a week of respite with other individuals his/her age. SHIP has estimated that the average cost of such services will be approximately \$5,000 per person during the course of the year. FFP reimbursement for these types of services could be included in a waiver as well. MRC is actively working on a TBI waiver with DMA and will submit to HCFA early FY'00. This successful application would also cover a portion of this expansion.

\* \$2,500,000 would allow SHIP to purchase services for about 500 individuals.

**Increase from FY '98**

FY '99 \$ - 0  
FY '00 \$ - 0  
FY '01 \$ 2,625,000

**Total Expansion from FY '98**

\$ - 0  
\$ - 0  
\$ 2,625,000

These budgetary requests, if appropriated, would address the service needs of over 1,100 survivors and their families, less than half of SHIP's applicant pool (*additional people served does not include the costs of transportation*). However that is in addition to the almost 500 served each year with the present budget. The total increased cost for maintaining and administering the services detailed above is \$18,165,000.

**SHIP Consumer Profile #1**

**Consumer:** Doris S.

Doris is a 33 year old woman who sustained a traumatic brain injury as a passenger in an automobile accident in 1978. She was comatose for 6 weeks. Neurological sequel include ataxia, impaired balance, impaired gait and decreased strength in lower extremities. Doris is treated with Haldol for paranoid symptoms and disorganization of thought process.

Doris has been residing in a one bedroom apartment in Northampton for the last 7 years. Staffing ratio is 1:1 24 hours/day. The apartment is leased by the Provider. She has ties to the community and will continue to reside in this area.

Doris is her own guardian.

### **Functional Living Skills:**

Doris requires 24 hour staff support. She is involved in a plan to allow her to remain unsupervised for periods of up to one hour. Doris is very impulsive and makes inappropriate phone calls to emergency personnel.

Doris is generally independent in her ADL's. She does require prompting to initiate such. Doris needs assistance planning and preparing her meals. Doris can budget and manage her weekly paycheck of \$40. She is responsible for purchasing her cigarettes and paying for recreation needs. She does require assistance with paying her bills and managing her social security money. Doris has some difficulty with ambulation due to an unsteady gait. She wears a lift on her shoe and has a brace for hyperextension of her knee. She needs prompting to continue to make use of these. Doris has difficulty making safe pedestrian decisions. Transportation is provided by staff.

Doris requires assistance with planning and organization. She has only recently begun to carry a date book and write scheduled events in it. She has not been able to retrieve this information with any degree of dependability.

### **Vocational/Day Program:**

Doris was injured while still in high school. The only pre-injury employment experience she had was very briefly as a waitress at a Brigham's. She quit because "she did not feel like working".

Through rehabilitation, Doris was involved in pre-vocational programs. She has done piecework at her home for one year and then was employed as a word processor. She has been employed for the past 6 years as a word processor. Currently, she works 2 hours/day 5 days/week. She requires assistance from a job coach in the beginning of each day and transitioning from task to task as well assuring the quality of the work.

### **Leisure/Recreation:**

Doris enjoys many social and recreational activities including dining out, going to the movies, visiting with her boyfriend, attending dances, concerts and actively participating in a monthly Head Injury Support Group. Doris is very willing to explore various leisure options with staff and is careful to budget her money so as to have enough throughout the week. Presently, Doris finds independent unstaffed leisure time somewhat unsettling and has requested to have no more than one hour alone.

### **Emotional/Behavioral:**

Doris has made significant improvement with emotional and behavioral issues including impulsively and aggression. Situation specific behavioral plans are in place for impulsively attempting to exit a moving vehicle and phoning emergency personnel for non-emergency concerns. Doris takes 4 mg/day of Haldol for behavioral issues.

### **Current Medical Needs:**

Doris has bursitis in her shoulders. She is seen as needed by a physical therapist and has been prescribed a regime of exercises which she does with staff prompting. Doris wears a brace on her right leg to prevent hyperextension. She also wears a lift in her shoe. Doris has intermittent problems with incontinence.

Doris' medications are monitored by a general physician.

Her current medications are:

Haldol:	4 mg/day
Cystospaz:	.45 mg/day
Genora:	1/35-28 birth control pill.

### **Current Immediate Problems/Concerns/Significant Issues:**

Doris' main concerns at this point center around life issues such as her desire to obtain her driver's license, get married, have children and increase her employment.

### **SHIP Consumer Profile #2**

**Consumer:** Charlie

### **General Overview:**

At age 8, Charlie sustained a severe head injury in 1975 when hit by a car. He was in a coma three months. Neurological sequelae include dense left hemiplegia, significant short term and long term memory problems, problems with executive functioning, motor slowing and dysarthria. After initial hospitalization, Charlie was returned home and attended a day school in Greater Boston from 1975-1977. He then attended a residential school in Greater Boston from 1977-1984. He graduated from high school in 1985. Charlie has been in residential services since 1975. He is currently living in a supported living program in the Greater Boston area. He has an apartment with two roommates, leased by the Provider. Charlie receives case management services approximately 2-3 times per week and life skills training 10-15 hours per week. Charlie is his own guardian.

### **Functional Living Skills:**

Charlie is semi-independent, requiring case management services 10-15 hours per week to assist with budgeting and independent living skills. He requires no overnight supervision in his apartment. He is independent in all ADL skills. Charlie can utilize public transportation independently. He has gait problems due to the left hemiplegia. Charlie relies heavily on the visual environment for cues to assist with his significant memory problems. He is highly sensitive to external stimuli and distraction. Charlie utilizes an electronic day timer to organize his day, appointments, etc. He requires assistance to program the day timer on a weekly basis.

### **Vocational/Day Program:**

While in high school Charlie was employed by ABCD. Since 1989, he has been working at a vocational placement in an EEP slot. His jobs have included mail room work and janitorial work which he has been doing since 1992. He worked full time Monday-Friday, 8-4:30 PM. He has a good work history and ethics. He is relatively independent on the job. Charlie does not like janitorial work and has been looking for new employment for some time. Charlie is fully capable in the future of working towards more independence in an employment setting with supports.

Presently, he is attending a day program to refine his independent living skills and work on independent social skills with individuals his own age. He will be referred to Supported Employment upon completion of the day program goals.

### **Leisure/Recreation:**

Charlie is very independent in both leisure and recreational activities which include visiting with friends, movies, TV, Nintendo, listening to music, working on the computer, etc. He enjoys all sorts of activities that are not too physically involved. He has no difficulty with group involvement.

### **Emotional/Behavioral:**

Charlie has a history of depression which is being monitored by 1:1 weekly counseling with a LICSW. To date, he has required no hospitalization or medication for the depression. Charlie is generally in a good mood and always has a good sense of humor.

### **Current Medical Needs:**

Charlie is generally in good health. He is on no medications.

### **Current Immediate Problems/Concerns/Significant Issues:**

Charlie's current needs include:

1. New employment

2. Increase in socialization with peers his own age
3. Increase in independent living skills to increase overall independence.



## **SHIP Consumer Profile #3**

**Consumer:** Arthur

### **General Overview:**

Arthur sustained a traumatic brain injury in a motor vehicle accident in 1975. Arthur sustained a much less severe second head injury in 1986 when he fell off the back of a truck. The first TBI resulted in respiratory arrest and he was in a coma for four weeks. Arthur was hospitalized for approximately three months. He received outpatient therapies for about three years. Substance abuse problems exacerbated cognitive and behavioral problems which led Arthur to be admitted to a secure neurobehavioral program in 1990. He was at that program approximately ten months. He was discharged from the secure program in 1991 and was admitted to a 24 hour supervised community based residential program in Southeast MA. In 1993, Arthur was transferred to another community based residential program when the previous program closed. Arthur received respite services through the supported living program in this latter program until his current placement was found in October 1993. Arthur currently resides in Brighton in a 24 hour supervised community based residential program with three roommates. Arthur requires a structured schedule, reinforcement program and behavioral plan to manage his impulsively and cognitive deficits. Staff ratio for Arthur is 1:1 in the community and in the residence the ratio can be 1:2 depending on the other consumer needs. He requires 24 hour supervision.

Arthur is under the legal guardianship of his father. His father is also the Rep. Payee for SSI.

### **Functional Living Skills:**

Arthur is very independent with ADL's, laundry and chores. He needs cues to stay on task. He is supervised in the kitchen when cooking. Arthur is not independent in regards to transportation due to his impulsively, poor planning skills and potential for elopement for substance abuse. Arthur's money is supervised at all times.

### **Vocational/Day Program:**

Arthur has been in structured vocational settings but has in the past worked in a competitive work environment with the aid of a job coach. Arthur has had problems following break schedule, but expresses a strong desire to work. Arthur worked up to 30-35 hours per week in the past, but more recently has worked 10 hrs/week. Currently, Arthur is going through a vocational evaluation to assess his vocational potential. He attends three days a week/ 6 hours per day. Arthur requires a structured vocational setting using his behavior/point plan. This amount of structure and supervision could change gradually if Arthur makes progress.

### **Leisure/Recreation:**

Arthur enjoys bowling, billiards, basketball, bocci, cards, board games, and TV. He is very active in groups, needing cues to stay focused, but participates in most recreation activities offered. Individual leisure activities include watching TV, listening to music and occasionally a work search game. Arthur has difficulty following through with independent leisure activities. Arthur is very social and needs some contact with people.

### **Emotional/Behavioral:**

Arthur's only "real" emotional issue is his off and on anger towards his father. Occasionally, Arthur expresses anger over his situation in life, his age, his need for supervision, and medications. Behavioral problems consist of impulsively, agitation with very few recorded episodes of actual aggression in the past few years. Aggression has occurred as a result of substance abuse. Arthur has a plan to reinforce compliance, remaining on task, remaining calm, following directions which revolves around cues and leads to time-out if needed.

Arthur presents himself as not needing supervision and this can lead to Arthur becoming agitated often around meal preparation, and in the community. Arthur has supervised use of money due to past record of impulsive elopements to buy scratch tickets and/or alcohol. Alcohol has often led Arthur to be aggressive and more non-compliant in the past. Arthur's last hospitalization was in 1990 for management of these issues. Medication management for Arthur's behavior is via Lithium.

### **Current Medical Needs:**

Arthur's medications are monitored by a psychiatrist.

Arthur's current medications include:

Phenobarbital:	60 mg for seizure control. ( <i>Arthur has been seizure free for at least 2 years</i> )
Inderal:	100 mg/day for control of tremors.
Lithium:	1500 mg per day for behavior control
Panomicin:	500 mg per day for acne.

### **Current Immediate Problems/Concerns/Significant Issues:**

Arthur will continue to require 24 hour supervision in a community based residential program, including a behavioral plan in both the residential and vocational settings to manage his overall behavioral issues.

**14. 4120-6001 Head Injury Treatment Trust Fund**  
**FY'98 Funding: \$250,000**  
**FY '99 Funding: \$750,000**  
**Current FY'2000 Funding: \$750,000**  
**FY '01 Proposed Funding: \$750,000**

**Program Description**

The Trust Fund for Head Injury Treatment Services was established in Chapter 138 of the Acts of 1991. The fund assesses a \$125 fine against those convicted of driving under the influence or driving to endanger. Although exact figures are not available, it is well known that a large percentage of traumatic brain injuries are a result of motor vehicle related incidents. These are accidents where alcohol or drugs were involved therefore it is felt that those who have caused these "accidents" should contribute to a fund that would support their victims.

There are a wide range of cognitive, physical and behavioral impairments that are associated with this disability that will require life long services and supports. These services are costly and are often not reimbursable through third party payers because they are community-based as opposed to medically related needs. Services such as structured day programs, respite care, transportation, adaptive equipment, home modifications, substance abuse treatment, cognitive retraining, case management and others do not fit into a medical model of service delivery. Yet, the availability of the services will strengthen family systems thereby preventing crisis that result in institutionalization which ultimately costs the Commonwealth and its taxpayers much more money.

This account was activated for the first time in the FY'97 budget and is fully funded from the Head Injury Treatment Trust Fund. It is anticipated that some FFP can be generated out of this account.

<u>Increase from FY '98</u>	<u>Total Expansion from FY '98</u>
FY'99 \$ 500,000	\$ 500,000
FY'00 \$ -0-	\$ 500,000
FY'01 \$ -0-	\$ 500,000

**Reason for Expansion**

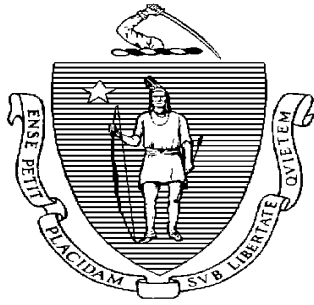
The Trust funds SHIP has access to this year are being used to provide residential services in Western Massachusetts; educate the courts and increase revenue collection; transportation; information and referral services; prevention initiatives; and community support services. Additional revenue is needed to begin to address the needs of people with TBI who are waiting for services from SHIP.

**15. 4120-6002      Head Injury Services Trust Fund**  
**FY'00: \$500,000 Estimated**  
**FY'01 Proposed Funding: \$3,000,000**

**Program Description**

The majority of individuals with traumatic brain injury are living at home with their families/significant others and receive little if any services. To date SHIP has received over 3,900 referrals which does not begin to represent the extent of this disability. In 1990 an estimated 28,000 people were injured seriously enough to result in death or require hospital-based care. For every death there are nine people who survive and are discharged home or to other health care facilities. This new account is seen as an opportunity to begin to reach out to these individuals and aging families by providing residential opportunities in the community which are presently limited due to restrictions in the Trust Fund expenditures as well as maintenance funding in the SHIP account.

The funding being requested is based on the anticipated collection of fines using the data available in previous fiscal years on the number of speeding violations written in the Commonwealth each year and includes administrative costs necessary to the management of these expanded services. Many of the services to be funded through this account would be considered for FFP reimbursement when Massachusetts has a TBI Home and Community Based. These funds will be used to provide expanded services to people being served in the SHIP program as well as new people from the waiting list. (See proposed additional funds request in 4120-6000)



**MASSACHUSETTS COMMISSION FOR  
THE DEAF AND HARD OF HEARING**

**Barbara Jean Wood, Commissioner  
210 South Street, 5<sup>th</sup> Floor  
Boston, MA 02111**

**MASSACHUSETTS COMMISSION  
FOR THE BLIND**

**David Govostes, Acting Commissioner  
88 Kingston Street  
Boston, MA 02111**

**MASSACHUSETTS REHABILITATION COMMISSION**

**Elmer C. Bartels, Commissioner  
27-43 Wormwood Street  
Boston, MA 02210**